What are the views and experiences of daily life for women living with visible, physical disabilities in Papua New Guinea?

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ABSTRACT

Papua New Guinea (PNG) developed its National Policy for Disability (NPD) in 2005. The NPD aims to remove barriers that hinder the right of people with disabilities to live a life that is no different to able bodied people in PNG. This policy also reflects PNG's commitment to the ratification on the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). This study examines the views and experiences of women living with disabilities in rural PNG. This is the first time these narratives have been gathered for research purposes. This study adopts a qualitative approach and used the three theoretical underpinnings of Interpretative Phenomenological Analysis (IPA) approach─ phenomenology, hermeneutics and idiography─ to develop the research methodology and method. Semi-structured individual interviews from five women with visible, physical disabilities in rural PNG were used to gather narratives about their daily lives. The interviews were transcribed in Tok Pisin, translated to English, and five narratives were developed from the scripts, to capture the voices of the participants about their lives and concerns. Key findings from these narratives indicate that both the socio-cultural practices and the physical environment substantially influence the women's level of involvement in their communities. The narratives also revealed that the women's daily lives are strongly influenced by how non-disabled perceive disability and disabled people in PNG. These influences include negative self-perceptions, discrimination, marginalisation and being disadvantaged in their communities. It is suggested that current policies and practices that relate to women and people with disabilities should include programmes that raise awareness at the community level about inclusive practices and strengthen social participation and empowerment activities and programmes for women with disabilities at community levels.

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DEDICATION

In loving memory of my Late Mother:

Helen Kukie Pangura Yenas
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You left too early to see the completion of this thesis, but your spirit stood by me and cheered me on in every step of this journey. At my lowest, when there seemed to be no light, I felt your presence. You have always wanted me to complete this journey. Your dream for me to reach this height has become a reality. This is for you, Mum. I know you are proud and smiling down from the world unseen.

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CHAPTER ONE

SETTING THE SCENE AND INTRODUCTION

This chapter sets the scene for this thesis. The situation for women with disabilities in the global context, in the developing world, and in the Pacific region is briefly examined. Then what is happening for women in rural communities of PNG is overviewed, including how these issues affect women with disabilities who live in rural remote settings. Thirdly, I provide a brief information about PNG, and outline PNG's historical context in terms of legislation relating to people with disability and women. I then present the focus of this study, my own motivation for undertaking this research topic, and the study aim. Finally, information about the potential significance of this study, is presented.

1.1 Background

> *"Gender is socially constructed based upon one's biological sex"*
>
> (Henderson, Bedini, Hecht, & Schuler, 1995, p. 1).

> *"*[Being female and having a disability are]*…are most crucially understood as socially constructed and historically mediated categories of experience"*
>
> (Gliedman & Roth, 1980, as cited in Harris & Wideman, 1988, p. 116).

These two statements emphasise that both gender and disability have a social meaning and a social stigma which contributes to the difficulties that people with disabilities face in their everyday lives. The combination of gender and disability further compounds the possibility of stigma around disabilities and makes life complicated for women with disabilities (Harris & Wideman, 1988). This can and does affect their views and experiences of living with a disability. In this thesis, the phrases *women with disability'* and *women with disabilities* are used interchangeably to refer to women who live with some form of disability. The word *women* is used before *disability*, as I view and position women with disabilities as women first. The words *disability* and *disabilities* are used after the word *women*, because the participants who took part in this project are women in their own right. Thus, they are identified as women first. The disability they have is something they happen to live with as all have had their disability from birth.

However, this thesis also acknowledges the influence of the social model of disability on the choice of topic and participants (Oliver, 1990). At times in points of discussion rather than disability the term impairment is used. The phrase *disabled women* is used as an acknowledgement that disability is socially constructed. In all cases where I use the term *disabled*, there is no derogatory connotation.

1.1.1 Women with disabilities-the global context

A growing body of contemporary literature reveals that in the twenty-first century women with disabilities are still marginalised in their societies and often encounter significant challenges in different physical and social aspects of their lives (International Disability and Development Consortium [IDDC], n.d.; Nosek & Hughes, 2003; RI/Global Work Women and Disability [RI/GWWD] n.d.; Tarasoff, 2015; Women Watch Information and Resources on Gender Equality and Empowerment of Women [WWIRGEEW] n.d.). Women with disabilities experience discrimination because of their gender and their disability (Groce, 1997; United Nations Division for Social Policy and Development Disability [UNDSPDD], 2017, n.d.). When disability intertwines with gender, life can become more complicated for them (Harris & Wideman, 1988). This duality places them at particular risk of experiencing violence and abuse of any form, which leaves them personally vulnerable and at risk of exploitation (Nosek, Hughes, Taylor, & Taylor, 2006; Plummer & Findley, 2012; Tarasoff, 2017; Young, Nosek, Howland, Chanpong, & Rintala, 1997). Literature also suggests that in contemporary society, the requirements of disabled women are forgotten, and they lack access to opportunities enjoyed by non-disabled mainstream populations (Hughes, 2006; Tarasoff, 2015)

Not being recognised in society and not having equal opportunities often leads to social isolation and exclusion (Nosek, Foley, Hughes, & Howland, 2001; Nosek, Howland, Rintala, Yopung, & Chanpong, 2001; Nosek, Hughes, Swedlund, Taylor, & Swank, 2003), which can be more debilitating for disabled women with disabilities than their physical disabilities or medical conditions (RI/GWWD, n.d.; WWIRGEEW, n.d.). While more information about disabled women is growing and becoming available, this group remains "an under-researched area of study by

both disability and feminist researchers" (Traustadottir, 1992, as cited in Henderson et al., 1995, p. 17).

In respect to the lives of physically disabled women, research suggests that women in this group encounter significant challenges and difficulties in both public and private arenas when trying to attain basic services. Particular barriers for members of this group include "access to adequate housing, health, education, vocational training and employment" (UNDSPDD, n.d. para. 1). Similar to women with other disabilities, women with physical disabilities are often victimised, seen as unproductive and/or helpless (Young et al., 1997) and can experience multiple forms of discrimination (Spratt, 2013; Stubbs & Tawake, 2009).

1.1.2 Women with disabilities-the developing world context

Most of the world's disabled population live in the developing world (Priestley, 2001; World Health Organisation [WHO], 2011) and women make up more than half of this population (Groce, 1997; United Nations, n.d.-b). While the population of women with disabilities is increasing, different factors, such as social context and culture, contribute to affect their quality of life. However, "uneven economic and political developments mean that … disability affects [women] differently in different societies" (Priestley, 2001, p. 3). Thus the issues faced by the disabled population in wealthy developed nations with significant welfare provision and disability support are different from those in the developing world (Priestley, 2001). While key aspects of the difficulties that all disabled women face are universal, "the complexity and severity of these problems take on additional weight when viewed in the larger contexts of dire poverty, rigid class systems, and poor resource bases" (Groce, 1997, p. 179). As Groce (1997) explains, a "woman's social and economic class, her marital status, her family's social networks, her level of education, and her specific type of disability will make a dramatic difference in her quality of life and her ability to make choices"(p. 179). For example, the quality of life of a physically disabled lower-class rural woman in the developing world who uses a wheel chair will be dramatically different from that of the daughter of a prominent politician, with a similar physical disability who also uses a wheelchair, even if they both are in the same community. A rural-lower class woman of a Western country has resources

available to her that a female villager of a developing Pacific Island (PI) nation does not.

Most women in developing nations live in difficult positions (Groce, 1997; RI/GWWD, n.d.), yet very little research has been conducted that looks deeply into the lives of women with disabilities in the developing world (Groce, 1997). While issues of marginalisation and exclusion affect all disabled women, the issues of disabled women in developing nations are far more severe than those in the first-world countries (RI/GWWD, n.d.). This is particularly the case in the PI nations, of which PNG is one. Women with disabilities in PNG encounter extreme marginalisation and exclusion from involvement in their society. This leads to the women living in isolation and silence where they are prevented from speaking up for themselves. This point will be elaborated on later in the thesis.

1.1.3 Women with disabilities-the Pacific region context

According to Sands (2005), women with disabilities "do not generally benefit from international human-rights laws and agreements, or from development discourse and practice. The interconnection between disability and gender identity is largely invisible within women's rights, disability rights, and development agendas" (p. 51). This is "particularly evident for Pacific women" (Sands, 2005, p. 51) with disabilities living in the Pacific region where the effects of the disability are compounded by "multiple … forms of discrimination" (Stubbs & Tawake, 2009, p. 99). This intersectionality includes aspects such as limited education, unemployment, poverty, isolation, exclusion, and lack of access to basic health services (Stubbs & Tawake, 2009). However, here too, the social effects of disability can be experienced differently depending on the condition and type of disability and according to where each disabled woman lives. These differences of social experience can also be due to cultural (Mapsea, 2006), socio-political (Bomen, 2017; Sands, 2005; Spratt, 2013), socio-economical (Spratt, 2013) and geographical (Mapsea, 2006; Spratt, 2013) aspects of each of the countries in the Pacific region. However, they share some common experiences on issues including: violence, social and economic status, poverty, education, employment, basic services and isolation (Sands, 2005; Stubbs & Tawake, 2009). Although a heavy emphasis on kinship and bonding is embedded in Pacific societies (Pacific Islands Forum Secretariat [PIFS], 2013), women must still contend with carrying

a low status within their villages and communities (Stubbs & Tawake, 2009). Such cultural norms contribute to the multitude of challenges and difficulties experienced by those with disabilities in the Pacific Island countries (PICs).

There is limited academic literature available on research conducted with women and girls with disabilities in the Pacific region (Spratt, 2013; Stubbs & Tawake, 2009; Thomas & Legge, 2009). As a result, very little is known about their lives and experiences (Groce, 1997; Sands, 2005), their situations and the issues they have that impact on their rights both as *women* and as *women with disabilities*. A specific study conducted by Spratt (2013) has examined the situation and needs of women with disabilities in three PICs: Kiribati, Solomon Islands and Tonga. She conducted situational analysis interviews with women with disabilities. These interviews focussed on sexual and reproductive health. In particular, this study indicated that Pacific women with disabilities experience more violence than Pacific women without disabilities. The author also acknowledges the "lack of published evidence" (Spratt, 2013, p. 29) on the situation and needs of disabled women in the PICs. Stubbs and Tawake (2009) conducted a survey across various PICs, including PNG, which focussed on issues and challenges faced by women with disabilities in the Pacific with the goal of analysing "social and economic factors impacting on their human rights" (p. 7). Their findings also revealed that women with disabilities in the Pacific experience physical and sexual, as well as discrimination in many other aspects of life including social participation in their communities.

Although literature acknowledges that the majority of women with disabilities live in the developing world, Articles 3 and 6 of the World Bank (2009) Report indicate that:

> Many women with disabilities report feeling "invisible" in the development context and largely absent from the development agenda. Even when gender considerations are incorporated into development projects, the specific perspectives and needs of women and girls with disabilities are seldom sought or incorporated. (para. 1)

This issue has been noted by several academics and organisations in other studies conducted on women with disabilities (Boylan, 1991; Groce, 1999; Sands, 2005;

Yeo, 2005). Equality, empowerment and recognition are treated as significant attributes for women, and these notions reflect the idea of universal rights for women as indicated in the UN Convention of the Persons with Disabilities (United Nations, n.d.-a). In terms of developmental initiatives, including research, however, women with disabilities are thus "not recognised as a priority" (Sands, 2005, p. 52), rather they are recognised for their neglected rights. However, in cases where they are identified, the focus is on "rehabilitation, impairment, prevention, healthcare and the provision of technical aids and equipment" (Sands, 2005, p. 52). This indicates the need to conduct research and document information on various aspects of the life of women with disabilities including their views and lived experiences.

1.2 Introduction

As indicated, women with disabilities are more disadvantaged than able-bodied women in PNG. However, formal evidence for this is hard to find. My thesis proceeds with an understanding that several national policies that are developed in PNG reflect PNG's commitment to the international treaties and legislation that PNG has ratified. These national policies guarantee that women with disabilities in PNG should enjoy the same human rights as all able-bodied people, to live a life free from any sort of harm.

Papua New Guinea is the largest island country in the Pacific region. It shares borders with Indonesia, Solomon Islands and Australia. PNG gained independence in 1975 (Geissinger, 1997). Port Moresby is its capital city (Bomen, 2017). PNG has a land mass of 462, 860 km^2 with a population of eight million and rapidly growing. About 85% of the population live in remote and rural communities (Hanson, Allen, Bourke, & McCarthy, 2001).

PNG is a culturally diverse nation with 800 plus different languages and two national languages, Pidgin (Tok Pisin) and Motu (Winis, 2013). The "main languages used as a medium of business communication are English and Pidgin. PNG is situated in the tropics and has rugged mountains, swamps, lakes, rivers and seas. This sometimes makes service delivery very difficult for all government sectors" (Winis, 2013, as cited in Bomen, 2017, p. 14).

PNG is categorised as a *developing* or *least developed* nation (Aisi, 2014; Costa & Sharp, 2011). PNG's economy is "highly dualistic, with a natural resource-based export economy supporting a small number of people, and a subsistence/semi subsistence rural economy supporting the livelihoods of more than 80 per cent of the population" (Asian Development Bank, 2006, as cited in Cahn & Liu, 2008, p. 134). The living conditions for the people differ greatly: while some people can earn relatively high incomes, others are "poor, [live in] remote [areas] and [are] marginalised, often because of where they live … the most disadvantaged people have little government influence or support" (Hanson et al., 2001, p. 10). The majority of the population support themselves through rural livelihood activities such as agriculture (Cahn & Liu, 2008).

1.2.1 PNG Disability Policy

In 2005, the PNG Government introduced its disability policy entitled the National Disability Policy (NDP)—which is the country's national strategy and action plan for the disability sector. The purpose of the NDP is to develop an inclusive society and to "create awareness on the needs [of] people with disabilities and identify priority areas for action to dismantle barriers hindering the full participation of people with disabilities in the social and economic life of Papua New Guinea" (Department for Community Development and Religion, [DCDR], n.d., p. 77). This policy was later reviewed and renamed in 2015 as 'The National Policy on Disability 2015-2025' (NPD) (Department for Community Development, [DCD], n.d.).

This landmark document also serves as a commitment to the ratification of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), which emphasises the removal of barriers for persons with disabilities (DCD, n.d.) The vision of the NPD is to *Remove Barriers: Make Rights Real* (DCDR, n.d, p. 88) so that all people, including those with disabilities, can be fully included in society. The NPD has action plans which are intended to be used as a guide for government and non-government organisations, service providers and individuals to create an inclusive society that values all people. The policy aims at promoting and encouraging responsible actions to remove obstacles and barriers that may impact or hinder the rights of people with disabilities. When the policy and its vison are fully implemented, people living with disabilities should

be able to enjoy the same rights as everyone else and to live a life that is no different to able bodied people (DCDR, n.d).

1.2.2 National Policy for Women and Gender Equality

In 1991, PNG also initiated its first *National Women's Policy*. The aim of this policy was to build a strong mechanism for gender equality for all women in PNG. This policy should also apply to women with disabilities. The major achievement of this policy was the establishment of the *Office for the Development of Women* (DCD, n.d., p. 5) This office was created to fulfil the commitment by the PNG Government to improve the situation of women in the country (DCDR, n.d). This policy was also revised and retitled the *National Policy for Women and Gender Equality 2011-2015.* The purpose of this policy is to initiate, endorse and effect equal participation through economic, social and political development so that women have access to the same opportunities as men (UNDP Papua New Guinea, n.d.). The policy also provides a framework that will improve development priorities for all women in PNG.

Some of the other key areas that PNG has entered into in the international, regional and national platforms in terms of women's human rights include: "the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW), the Beijing Platform for Action… and a number of South Pacific Platform for Action" (Papua New Guinea [PNGDoH], 2014, p. 3) and also the Common Wealth Plan of Action on Gender Equality (2005-2015) (PNGDoH, 2014).

In September 2013, PNG ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This document promotes the rights of all people with disabilities to live and work alongside their non-disabled peers as full citizens and encourages a barrier free society at all levels. PNG has also developed a national policy in respect of this commitment – the PNG National Policy on Disability (2015-2025). This document too guarantees full inclusion and a barrier free society for all people with disabilities in PNG.

Although PNG has a disability policy in place, research conducted recently into inclusive education practices in a number of schools in PNG has revealed that the notion of inclusion in PNG is still underdeveloped. Contributing factors include

PNG's demography, culture, geography, societal structures and attitudes of policy implementers and individuals (Bomen, 2017; Mapsea, 2006; Rombo, 2007; Torombe, 2013; Winis, 2013). These factors impact on PNG's slow progress in adopting and executing new ideas and policies effectively in educational settings despite a significant need to bridge policies and practices in school settings (Rombo, 2007; Torombe, 2013). If this gap exist in the school settings, it can be suggested that people with disabilities at the community level are more likely to be excluded in terms of social and educational participation, and wellbeing. In this respect, the current study is significant as it goes beyond the previous studies conducted in the area of disability and inclusion in PNG.

1.3 Study Focus

The focus of this study is specifically on women with disabilities in PNG. As I begin this research journey, I acknowledge my identity as a Melanesian woman of colour from the Pacific region. I acknowledge this aspect of my identity and the lived experiences of my life's journey that have contributed to my development as an individual. These have been critically important to my research and the narratives of my participants. My experiences include, being the eldest in my family, and female. As the eldest in my family, I am naturally positioned to lead, serve, guide and to ensure my younger siblings are cared for and are content. As a female growing up in my society, I have a responsibility to help in the home with household chores and to entertain, accommodate and make my visitors feel welcomed and treated with respect. I am the mother of three boys and a colleague to my workmates. As a mother, I am required to attend to my sons, provide for and nurture them as well as attend to household chores. In my profession as an educator, I am required to perform my duties as a professional at a required level. Given the role to lead in certain aspects of my career puts me in a position to exercise my strengths which have enabled me to recognise my potential. In embracing the identity positions of—eldest, female, mother, and educator—, I own the responsibilities that accompany them. I acknowledge that there are challenges and difficulties involved in growing up as a woman in my society.

1.3.1 History of disability equality in PNG

Historically, men and women living with disabilities, including women, have had an extremely low status. In 1975, PNG gained its independence and adopted

Gender Equality Goals which are enshrined in its Constitution (PNGDoH, 2014). Two of the five National Goals in the PNG Constitution promote gender equality. Goals 1 and 2 are *Integral human development* and *Equality and participation* respectively (PNGDoH, 2014, p. 77). The other provisions in the PNG Constitution that promote gender equality are "the basic rights which include the rights to freedom and life, as well as freedom from inhuman treatment" (PNGDoH, 2014, p. 77). Although the principles which protect people against discrimination can also apply to people with disabilities, policies designed to benefit people with disabilities were not introduced until 30 years later.

1.3.2 How disability is viewed in PNG

With PNG's diverse cultures, the people of PNG have different attitudes towards disability. The way of interpreting and understanding disability varies between the different communities and cultures (Mapsea, 2006). Generally, the attitudes PNG people hold towards 'disability' is often associated with cultural beliefs (Byford & Veenstra, 2004; Whitzman, James, & Poweseu, 2013) where "culture constitutes a central element for the understanding of societies' beliefs and practices related to … disability" (Kuzma, Ramalingam, & Karthikeyan, 2016, p. 14). While culture plays a role in understanding and interpreting disability, it also creates barriers in certain aspects of people's lives. For example, the people of Okapa, Eastern Highlands, have a common belief that a child's disability is a form of punishment from bad spirits for the parent's sexual act in a forbidden area, while the people of Bunabun in Madang believe that transgression of taboos by a pregnant woman can result in her baby acquiring congenital abnormalities at birth (Kuzma et al., 2016).

Such cultural beliefs and practices add to the barriers in the lives of women with disabilities in PNG, thus exposing them to different forms of discrimination and stigma. They continue to live as a marginalised group in society who are vulnerable to different forms of abuse (PIFS, 2013; RI/GWWD, n.d.; WWIRGEEW, n.d.)

According to (Flynn, 2011, July 5), the introduction of Christianity has also influenced the way people perceive disability. When PNG culture is mixed with Christianity, it "can often be exclusionary, despite preaching tolerance and respect

as core values" (Flynn, 2011, July 5, para. 4). Some parts of the Bible can be misinterpreted as suggesting disability is a curse from God, for example, Leviticus 21: 16-23. When this belief is combined with traditional beliefs, people assume that disability is associated with the family's wrong deeds, and thus can be viewed as punishment from God. Thus, 'disability' brings shame and there is a tendency to fear people with disabilities (Flynn, 2011, July 5). Such beliefs can often deny both men and women with disabilities access to full inclusion in communities.

Gender inequality is imposed by the cultural system (Hinton & Earnest, 2010; PIFS, 2013). This cultural obligation continues to devalue women leaving them exposed to a wide range of societal injustices (Vali, 2010) and different forms of abuse which leaves them vulnerable (Hinton & Earnest, 2009, 2010; Vali, 2010; Yawi, 2012). In contemporary PNG society, in terms of rural livelihoods women are "are increasingly 'cash' cropping as well as producing food for subsistence, and much of this cash activity is in the 'informal sector" (Fairbairn-Dunlop, 1997, as cited in Cahn & Liu, 2008, pp. 133-134).

1.4 Motivation for the study

Several different experiences motivated me to embark on this study journey. I consider them important to share as they are stepping stones to raising awareness of the situation of those whose voices are ignored, and to advocate for and with them in realising their potential and dreams. I was first introduced to the concept of disability and inclusion during my teacher training. My interest in this area was heightened in my first encounter with deaf children in the classroom when teaching in a rural school in PNG. This interest developed into my becoming a sign language teacher for deaf children. This experience landed me the role of teacher in the Special Education Resource Centre (SERC). I was then given the job of lecturing in special education courses at a teachers' college in PNG. Taking the paper *HDCO-521 Contemporary Issues in Disability and Inclusion Studies* at the University of Waikato has broadened my understanding of disability, the theories around it, and issues relating to the complex nature of disability.

My first experience and what sets the foundation for my passion on the field of disability was an elective course I took during my teacher training. The elective paper had two assigned tasks. The first was to construct tactile shapes for a

visually impaired child and the second was to learn the Melanesian Sign Language (MSL) from the beginner level to the advanced level.

With the MSL experience, I took part in thirty one-hour home contact sessions every Saturday morning to work with a six-year-old child who was profoundly deaf. I was required to plan lessons and teach the child during the one-hour sessions. I taught and helped the child to sign letters, fingerspell and sign words as well as sentences in MSL. We also used visual objects as they are necessary to help the child understand what was covered in the session. This experience set the foundation for my passion and how far I have come.

Another experience that sparked my interest in the area of disability was when I taught in rural school in PNG. At that time, I had two deaf children in my class. The two students were eager to learn but they were struggling because of deafness. When I used MSL to teach them, they could not understand because they were not taught MSL before they started school. They were able to understand the natural signs. At that time, I would give work to other students and attend to both individually. After few weeks of helping these students, there was progress but at a very slow pace.

In 2008, I was given a position as a deafness education teacher to teach students with deafness. I was given a small office space in a school to work with deaf children. I planned and taught lessons to the deaf children using MSL. We drew, wrote and did activities together that helped them learn. During the weekends, in my free time, I would go to their communities and teach MSL to their families and community members. This experience has strengthened my interest in the field of disability.

Another experience that motivated me to undertake this study was my experience of working with children and people with disabilities at the Special Education Resource Centre (SERC). I was involved in carrying out different activities including: community outreach programmes at the local remote communities, school visits, assisting teachers to develop Individual Education Plans (IEPs) for students with special needs, and facilitating school in-service programmes for teachers on various Inclusive Education topics. This experience led me to a New

Zealand (NZ) Aid Scholarship to begin studying at postgraduate level in New Zealand.

The paper *HDCO-521 Contemporary Issues in Disability and Inclusion Studies* which I took at the University of Waikato has challenged and inspired me greatly. The content of this paper was about disability studies and its movement and the questions and the complexity and issues surrounding disability. The paper helped me gain in-depth understanding about different western theories of disability. It also helped me understand the different discourses surrounding disability. I gained an understanding of how people with disabilities have become activists and the importance of listening to the voices of disabled people. They became the activists in the disability movement which gives rights to people with disabilities to be educated in the classroom with everyone and to be included in society. They became so vocal in the disability movement that people with disabilities have been given the opportunity to attend the same schools as everyone and, have jobs like everyone else. With this study, I came to understand that the society can be the best place to live if there is no negativity.

The sixth thing that motivated me to take this study is I am passionate about seeing all people being treated equally. My experience of working with people with disabilities has broadened my understanding of how people with disabilities feel and have given me an experience in seeing how people with disabilities are marginalised, segregated, discriminated, and labelled differently from everyone else. As a non-disabled person, I recognise the importance of creating space for the voices of the disabled people, thus their voices are paramount in my thesis. In my thesis I allow space for women who are disabled to have a voice by sharing their views and experiences with me.

I also believe that changing people's attitudes can help break down the barrier of inequality, unfairness and injustice. I believe that changing our attitudes in the way we look at things, and learning to accept that we are all differently abled can make society the best place to live. It is not being *disable* or *abled*. It should be about communities giving space to everyone to use their different abilities for the good of society.

1.5 Study Aim

The aim of this study is to give voice to women with disabilities in the PNG rural community through exploring the views and experiences of daily life for women living with visible, physical disabilities. These women are a group who often remain invisible in terms of development agendas including human rights agendas and are thus "not recognised as a priority" (Sands, 2005, p. 52) for either policy or research purposes. In cases where they are identified, the focus is on "rehabilitation, impairment, prevention, healthcare and the provision of technical aids and equipment" (Sands, 2005, p. 52). Their exclusion in development and human rights agendas indicates the need to conduct research and document information on their life experiences in a way that includes their 'views and lived experiences'. The focus of this study is to encourage participants to speak about their daily lives and to make meaning of their lived experiences (Smith, Larkin, & Flowers, 2009)

1.5.1 Research Question

The research is focussed on providing information that will contribute to a better understanding of how the *National Disability Policy 2015-2025* and the *National Policy for Women and Gender Equality 2011-2015* might be implemented in rural settings in PNG. It explores whether the women with visible, physical disabilities might be aware of the existence of these policies and their extent to which they promote inclusiveness and protect their rights; if not, how awareness in this area might be cultivated for the benefit of this group of women. The research question which guided the focus of my study is as follows:

> What are the views and experiences of daily life for women living with visible, physical disabilities in a rural setting Papua New Guinea?

1.5.2 Women's place in PNG

Culturally, PNG is considered a patriarchal society. Men have the power and authority to lead while women are traditionally expected to manage the home, raise children and cultivate gardens (Yawi, 2012). Generally, women encounter very difficult challenges, experience injustice and receive unfair treatment (Vali, 2010). With a strong cultural preference for males in PNG, women are often depicted in society as less ambitious, unproductive and powerless (Yawi, 2012).

This situation leaves women to be vulnerable to different forms of abuse and violence (Hinton & Earnest, 2010; Phopo, 2015; Vali, 2010).

Economic structure- Despite women performing important roles in commercial agriculture, men continue to make most of the decisions in terms of marketing the crops (Moretti, 2006), especially in commercial products such as coffee, cocoa, palm oil, and vanilla (Cahn & Liu, 2008). Although women work hard, they usually have very limited control/power in decision making over resources and income (Phopo, 2015). Alongside abled women, women with disabilities in rural communities experience significant hardships but they are also confronted with difficult experiences. These challenge them to be self-reliant by *working hard* in order to provide for themselves and their families (Hinton & Earnest, 2009). *Working hard* in a rural PNG context refers to gardening and selling their produce, selling other items, or doing small scale business to sustain themselves and their families. Because of the societal context, women with disabilities in PNG are forced to live lives of self-reliance, by relying on themselves. Their level of self-reliance reliance depends on the condition of their disability and the type of support available. Family support is available because of the strong Melanesian cultural value of family bonds (PIFS, 2013). However, at times, this support may not be available due to various reasons, including: the number of children to care for in the family, having too many other responsibilities outside of the house, or the type of love, care and support of her family. Economic constraints and poor economic circumstances (Hinton & Earnest, 2010) affect the quality of life for this group of women greatly, thus leaving them to experience poverty. Poverty in this case is not only in terms of money but is also associated with vulnerability (Phopo, 2015).

Education- Women with disabilities in rural areas of PNG are disadvantaged in terms of any level of education. The option for educating a person with disability is rarely considered an alternative. Thus, women with disabilities in PNG experience difficulty in attaining education due to compounding factors including: cultural beliefs (Mapsea, 2006), socio economic status (Bomen, 2017), school buildings not disability accessible (Groce, 2004), and insufficient training for teachers; appropriate teaching resources and unwillingness to include them in the classrooms (Groce, 2004). Furthermore, school fees, lack of funds and the

economic status of the family determines whether a girl with disability goes to school (Groce, 2004). Finally, the availability of support from the family are also factors that determine whether a girl with disability attends school or not (Groce, 2004). The lack of knowledge because of high rate of illiteracy complicates life further for them.

Health and Reproductive Choice- Throughout life in PNG "poor social and economic circumstances affect women's health" (Hinton & Earnest, 2011, p. 6). However, in rural areas of PNG, women are faced with significant challenges in terms of geography, societal context, economic constraints and the political aspects of the rural villages where they live, thus, most of their health needs and issues are unmet (Hinton & Earnest, 2009). As Vlassoff (1994) suggests "women's lower status influences their health in many ways (p. 1249). Women with disabilities in remote areas are further disadvantaged because their disability compounds the issues and challenges that abled women face.

Support- Generally, women in rural PNG communities have limited choices "about where and whom they might turn to for support, guidance, advice, information and assistance. Because they are more isolated, [they] tend to have greater …risks and less ability to deal with those risks" (Leipert & Reutter, 2005, as cited in Hinton & Earnest, 2010, p. 224). Women with disabilities are at an increased risk of facing the challenges abled women are experiencing, but continue to live with silence as their concerns are unheard and needs are unmet.

Overall, while all women can experience many disadvantages in PNG, disabled women are more vulnerable and are at higher risk of any form of abuse and are also multiply disadvantaged (United Nations Enable, n.d.). It is not uncommon for perpetrators to take advantage of and exploit them because of their disability and vulnerability. In many cases, they are unable to defend themselves and do not often receive any support (FemiliPNG, 2018).Under these circumstances, women with disabilities are more disadvantaged than able bodied women in PNG, however, formal evidence for this is hard to find.

1.5.3 Voice of Women with Disabilities in PNG

The voices of women living with disabilities in PNG is hard to find in PNG disability research. The scarcity of information on their voices and experiences

suggests that they are unrecognised in terms of development. Hence, this population in PNG encounters issues that can be challenging and more difficult than for women who are not disabled (Spratt, 2013; Stubbs & Tawake, 2009). Sands (2005) argues that "specific experiences of women with disability remains essentially [unexplored,] unacknowledged and unaddressed" (p. 52). This identifies a fundamental need to develop a voice for this group (Nixon, 2009; Sands, 2005; Spratt, 2013). Comprehensive research is essential to gather in-depth information on women and girls with disabilities in PNG in order to develop a voice for this marginalised group.

For women with disabilities in PNG to benefit from the international rights for people with disabilities, fully exercise these rights and have their specific perspectives and needs incorporated in development agendas, they should be given a space to voice their views and experiences. By sharing their day to day realities, their concerns regarding their situations can be heard and therefore can be addressed. This is the case in this thesis, as I allow space in Chapter Four (4) for the research participants to 'voice' their concerns through their narratives. When their concerns are heard and addressed, intervention measures and strategies can be incorporated into the existing plans and policies so that Article 6 of the UNCRPD, which is entirely devoted to the concerns of women with disabilities, can be fully achieved.

The study fills a gap in PNG research surrounding women with disabilities. As Stubbs and Tawake (2009) acknowledged, there is "limited data available on women and girls with disabilities in the Pacific" (Stubbs & Tawake, 2009, p. 12). Their voices are often unheard (National Disability Resource and Advocacy Centre, n.d.). Literature also emphasises the need to give voice to women with disabilities because their voices have not been heard (Nixon, 2009; Sands, 2005)

PNG has a disability policy in place, however recent research on inclusive education practices in a number of schools in PNG revealed that the notion of inclusion in PNG is still underdeveloped due to a number of contributing factors (Mapsea, 2006; Rombo, 2007; Torombe, 2013).

Contrary to the international policies, women with disabilities in PNG as well as in other Pacific island countries (PICs) feel discriminated against, marginalised

and oppressed by societal norms (Spratt, 2013). As a result, women with disabilities doubt their self-worth and value, both as *women* and as *women with disabilities*. Because of the way in which society is structured, these women continue to remain silent (Spratt, 2013). Nevertheless, "women with disabilities make significant contributions to their communities. However, while they have similar talents, skills and experience as other women, they may be more often under-recognized and have fewer opportunities" (Spratt, 2013, p. 1). This recognition has challenged and motivated me to speak up and write as a *woman* for *women with disabilities*.

1.6 Significance of this research

This study is significant in that it opens possibilities of a still-hidden group in PNG. It is hoped that it will provide insights into how to acknowledge and value their contributions and accomplishments in their daily lives. Findings from the views may produce factors that could impact on their rights as women to live a life that is no different to that of their abled bodied counterparts. Aspects of the above are in line with the aim of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (United Nations, 2006) which prioritises and acknowledges the value of the contribution made by persons with disabilities to their future well-being and development. I also believe that this study could be of some help to the government and non-government organisations [NGOs] such as the Red Cross or the Cheshire Homes and Callan Services for Disabled Persons that work with people (including women) with disabilities in PNG. The findings could also provide ideas to extend and improve the existing range of programmes and, organisational support available for women with disabilities.

Finally, I believe that findings in this study will support further research in the future and as a result encourage development and improvement to legislation and policy that promote the rights of all people with disabilities.

As well as speaking up for women with disabilities, my thesis also offers space for women with disabilities to have a voice through the voices of my research participants. I believe that giving them a voice can minimise and eventually eliminate the negative attitudes and perceptions towards women with disabilities, as well as the divisions, gaps and barriers that discriminate, marginalise and

suppress them in PNG's rigid male dominant structured society. According to the UNCRPD, women with disabilities have the right to be treated with respect and should enjoy the same basic human rights as everyone else (United Nations, 2006). Only when women with disabilities are treated with respect, will they be recognised, acknowledged and embraced through their contributions to society. In that way women with disabilities can feel valued for who they are and can acknowledge and embrace their identity and self-worth. This is supported by Article 6 of the UNCRPD which is entirely devoted to women with disabilities (RI/GWWD n.d.).

1.7 Summary of the Chapter

This chapter offers some understanding on the situation for women with disabilities in rural communities in PNG. Although women with disabilities experience similar situations in the global context, the situation for each woman with disability is different according to a number of determinants: her disability type; the condition of the disability; where she lives; the socio cultural practices; the political status; the economic factors and the belief systems and assumptions.

1.8 Thesis Overview

This thesis is arranged in six chapters. The first chapter has presented the background and the introduction. The background discusses the situation for women with disabilities from the global context, the developing nations and the Pacific region. It is followed by the focus of the study, the motivation for this study, the aim of this study and the significance of this study.

The second chapter comprises of three sections. These include—the definitions of the terms that will be used throughout the thesis; a brief summary of the social and medical model of disability; the theoretical framework of this study—Interpretative Phenomenological Analysis (IPA) — and a brief discussion about ableism and how the researcher works with this concept in this research.

The third chapter explains the methodology and the method that were employed in this research and its reliability and validity of this research, followed by the participant demography, the ethical considerations of this research and the method used to gather the narratives. It also discusses the process of the fieldwork, and the data analysis procedure used in this study

The fourth chapter presents the voices of the women participants in five case studies. Each case study begins with a brief background of each woman, her life story in a chronological order, and my reflection at the end of each case study from an IPA approach

The fifth chapter presents a discussion of the key themes that have emerged from the women's narratives in Chapter Four. Discussions are made in relation to the IPA's theoretical underpinnings based on the Husserl's philosophy on phenomenology reviewed in Chapter Two and Chapter Three. The sixth chapter ends the thesis and contains recommendations and a conclusion section.

CHAPTER TWO
THEORETICAL FRAMEWORK

2.1 Chapter Overview

This chapter begins with brief definitions of the terms used in this study—disability, physical disability and visible physical disability. The idea of disability as a barrier to full inclusion in society, rather than an individual deficit, is explored. I then explain how the concept of Interpretative Phenomenological Analysis (IPA) was chosen as the theoretical framework used in this study. Next I include a definition of IPA; the history of IPA; the three theoretical underpinnings of IPA; and previous studies conducted using IPA. I also outline how I have used this framework in this study and the justification for using it. In the fourth section, I include a brief definition of ableism and how ableism could affect how I as a non-disabled woman present the life narratives of the disabled women participants. I return to this discussion in the conclusion section of this thesis. A brief summary concludes this chapter.

2.1.1 Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) protects the rights of all people with disabilities. According to Article 1 of the UNCRPD, people with disabilities are defined as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 3). This article emphasises that all people with disabilities are protected, that they should enjoy the same rights as every other able individual, and that they have fundamental freedom in all aspects of their lives. This definition of disability is used as the basis for this research and allies with the concept of the social model of disability which seeks to change social attitudes and structures in society with the goal of creating a barrier-free society and ensure that government agencies, non-government organisations, and the general populace recognise that all people, whether able-bodied, disabled, or not disabled, enjoy the same human rights (McCallum, 2012).

2.1.2 Terms used in the thesis

For this thesis, physical disability is defined as: the result of a condition affecting mobility or upper limb disorders or motor co-ordination in terms of fine and gross motor skills…which has an impact on lifestyle, work, movement and independence (Hampshire County Council, n.d, p. 3). This definition is echoed by that of the World Health Organisation (2011), which defines "physical disability as any impairment which limit the function of limbs or fine or gross motor ability. Physical disabilities include impairments which limit other aspects of day to day activities. Visible, physical disabilities can be defined as physical disability that is observable or can be easily perceived by the naked eye. For example, a person sitting in a wheel chair can be referred to as a person with a visible, physical disability, because it is clear according to the naked eye that the person has a physical disability. Other examples include someone who has one leg shorter than the other and uses a crutch or crutches to move around, someone who has shorter upper or lower limbs, or someone who has missing limbs. These definitions are important, as they were used to isolate the demographics used to choose the participants for this research.

In PNG, most people with disabilities do not receive a medical diagnosis of their disabilities or their conditions. With this understanding, those who have visible, physical disabilities are classified as such because their conditions are obvious or are evident according to how (non-physically impaired) people view them. This definition does not refer to someone who is blind or visually impaired, nor does it refer to someone who is deaf and lacks access to proper sign language/communication training. Thus this definition does not refer to someone who has any non-visible disease, such as those that affect movement.

2.1.3 Disability

In the field of disability, the two frequently used models to explain the conditions of disabled people's lives are the medical model and the social model (Goodley, 2017). The medical model of disability is the more traditional model of disability. This model views disability as a problem an individual has (Oliver, 1996). The person is considered unfit or in some way considered lacking in physical or cognitive skills. The social model of disability locates the problem within society rather than the individual, and according to how society is constructed in terms of

the physical and social environment (Oliver, 1996; Shakespeare, 2006, 2014). Use of this model has radically changed how disability is perceived and supported. This is emphasised by Barnes and Mercer (1996, as cited in Barnes & Mercer, 1997), as below:

> The significance of disability theory and practice lies in its radical challenge to the medical or individual model of disability. The latter is based on the assumption that the individual is 'disabled' by their impairment, whereas the social model of disability reverses the causal chain to explore how socially constructed barriers have disabled people with a perceived impairment. (p. 1)

2.1.4 Medical Model

The medical model of disability views disability as caused by accident, illness or disease (Mulvany, 2000) and locates the problem of disability within the individual (Oliver, 1990, 1996; Shakespeare, 2014). This then needs medicalisation to correct or fix the condition (Oliver, 1996), usually by medical intervention and/or rehabilitation (Goodley, 2017). The aims of the treatment is to restore a person to normality (Oliver, 1990).

The WHO (n.d.) definition of the term 'disabilities', is used as an umbrella term that covers "impairments, activity limitations, and participation restrictions" (WHO, 2011, para. 1). WHO (2011), further defines the terms, impairments, activity limitations, and participation restrictions, with an emphasis on environmental factors also contributing to creating the disability of a person. This is an understanding from the latest version of the "International Classification of Functioning, Disability and Health (ICF)" (WHO, 2011, p. 29). WHO (n.d.) the terms individually as:

> [1] An impairment is a problem in body function or structure; [2] an activity limitation is a difficulty encountered by an individual in executing a task or action; while [3] a participation restriction is a problem experienced by an individual in involvement in life situations. (para. 1)

The above WHO definitions emphasise that disability is imposed on an individual in relation to their medical condition and that disability is the problem that limits or restricts an individual from performing certain tasks. Disability is viewed as a

personal problem or an individual tragedy, of the person which stems from functional limitations (Oliver, 1996), that would need medical treatment to be corrected (Mulvany, 2000). However, disabled people themselves and their advocates have argued that this view of disability has caused problems for disabled individuals and has imposed restrictions on them (Oliver, 1996; Shakespeare, 2014). The perception of an individual who is 'not normal' still becomes a problem of the individual when a standard of 'normalcy' is used as a guideline for both impairment and disability (Davis, 1997). The idea of normalcy affects how individuals with disabilities feel towards themselves as well as limits their opportunities to fully participate in the community. This can create isolation and exclusion (Oliver, 1990). In summary, the medical model focusses on the health aspects of the individual but does not consider the social aspects that restrict, discriminate, stigmatise, and isolate people with disabilities from full participation in society (Mulvany, 2000; Oliver, 1996).

2.1.5 The Social Model of Disability

The concept of the social model of disability was developed when people with disabilities rejected the limitations inherent in regarding disability as an individual problem or defect. The social model of disability comes from the Union of the Physical Impaired Against Segregation (UPIAS, 1976 as cited in Oliver, 1996) definition which states:

> In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (p. 33)

The above definition emphasises that people with disabilities are disabled because of the barriers in society (Oliver, 2013), including society's negative attitudes as well as the physical environment. The social model of disability recognises that disability is caused by the social structures that make up the society. It views society as the factor that excludes people with disabilities (Shakespeare, 2014). This model suggests that, in order for all people to be included in all areas and aspects of life, political strategies should be adopted to promote inclusion. Such a strategy would prioritise ways of dismantling and eradicating the disabling

barriers (Shakespeare, 2014). Shakespeare (2014) further argues that "the benefits of social approaches are that they shift attention away from individuals and their physical or mental deficits to the ways in which the society includes or excludes them" (p. 12). Oliver (1996) suggests that the social model of disability does not deny the connection of disabilities and illnesses within the human body, as illnesses and diseases can cause disabling conditions. However, this aspect of disability should not be pre-eminent.

This concept links with the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) which protects the rights of all people with disabilities. This UNCRPD definition adopts the underlying ideas of the social model of disability. Article 1 of the UNCRPD defines persons with disabilities as "those who have a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (International Paralympic Committee, 2012, p. 3). This definition addresses the concerns of people with disabilities and also promotes the idea that disabled people are accepted as regular members of society with the same basic rights as other (non-disabled) individuals and deserve by right to have the opportunity to become fully active members of society. By addressing the concerns of full societal inclusion, it provides a perspective that recognises the need to adapt social and physical environment that are constructed around able-bodied norms, such as buildings, road designs, and transport for the accommodation of all people with disabilities (Campbell & Oliver, 1996; Oliver, 1996; Shakespeare, 2014).

For example, it recognises the need for sidewalks and buildings to have wheelchair access and the need for sign language training so that members of the Deaf community will have means of communication with the general public. In this way, people with disabilities can be fully included in society rather than being isolated, or excluded. Within the above definitions of the terms— disability, physical disability and visible, physical disability," disability can be viewed as socially constructed (Shakespeare, 2014; Wendell, 1996). In terms of disability, social construction refers to how disability is created by structures of social thought. For example, people's attitudes and communication. People's use of language that is ignorant can influence behaviours that are exclusionary (Barnes

& Mercer, 1997). The social model requires that all disabling barriers to full inclusion should be addressed and where possible, fully removed.

2.2 Using Interpretative Phenomenological Analysis (IPA) in this Study

This study is set within the field of disability studies and was designed to explore the realities of daily life for women living with visible, physical disabilities. Following a social model approach, IPA, as a methodology and framework, was considered suitable for the study, as it facilitated a way to explore and understand a life-world phenomenon—in this case, the views and experiences of women living with visible physical disability in rural areas in PNG. IPA fitted well into the idea of a social model approach to disability, as IPA promotes the idea that people themselves are a valuable tool for understanding the social context in which they are located. In this study, IPA reinforces the standpoint idea that disabled women themselves are the best judges of the support they need in order to succeed in their lives. Each of the interview participants have their own individual experiences of their social and personal worlds (Smith et al., 2009; Smith & Osborn, 2004), therefore IPA was deemed the most suitable methodology to gain deeper insights into their lives (Charlick, Pincombe, McKellar, & Fielder, 2016; Kaspar & Kroese, 2017; Smith et al., 2009). The use of IPA also provided the opportunity to work towards an accurate interpretation of their personal accounts (Charlick et al., 2016; Pietkiewicz & Smith, 2014; Smith et al., 2009). Finally, IPA was chosen because this tool had been successfully used with small groups to gather rich and accurate data.

2.2.1 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is an approach used in qualitative research that is committed to exploring and understanding lived experiences of a particular phenomenon (Smith et al., 2009), and is an "examination of how people make sense of their major life experiences" (Smith et al., 2009, p. 1). IPA researchers draw their understanding from Edmund Husserl's philosophy on phenomenology (Pietkiewicz & Smith, 2014; Smith et al., 2009) which is "concerned with exploring experiences in its own terms" (Smith et al., 2009, p. 1). IPA recognises that people have different perceptions of the world according to their personal lives and experiences. IPA aims to explore these experiences to

make sense of and understand them (Smith & Osborn, 2004). This means researchers will concentrate on the significant moments of the daily life experiences of individual people "before moving to broader claims" (Charlick et al., 2016, p. 205), or affirmations about what these moments might mean. Thus IPA aims to "look in detail into how someone makes sense of life experience, and to give detailed interpretation of the account to understand the experience" (Tuffour, 2017, p. 1) to provide an in-depth understanding of a particular phenomenon (Mutch, 2013; Smith et al., 2009). As such, IPA fits a qualitative research framework that is/was designed to make meaning of the lifeworld of participants and is therefore a suitable theoretical approach for this research topic - studying the views and experiences of women with disabilities.

2.2.2 The Origin of IPA

IPA was first pioneered by Jonathan Smith in the field of psychology (Smith et al., 2009; Tuffour, 2017) when he did his doctoral study on transitions to motherhood. He studied transition as a normative, primarily positive, experience as opposed to a negative one. This phenomenological study explored how the transition from their first pregnancy to motherhood affected their identity. One of Smith's primary aims was to "develop a methodology to facilitate examining this which was often pathologized in research" (Smith, 2017, p. 303). The study focussed on exploring the psychological processes of women during this stage of their lives. It was considered that a remarkable concurrence of events and circumstances contribute to "personal and social changes" (Smith, 1999, p. 410) in the lives of these women whereby making such a transition an important aspect that helped them adapt to a new sense of identity (Smith, 1999). The researcher explored the "women's accounts of how transition was affecting their identity" (Smith, 1999, p. 409). Smith's study was conducted within an idiographic logic which used a single case by case analysis as the basis for the research findings (Smith, 2004). This was considered important as it allowed space for the research to become a "significant contribution in its own right which has been sorely neglected in psychology" (Smith, 2004, p. 42). Since then, IPA has gained popularity, not only in health psychology, but also as a useful qualitative research tool in contemporary studies. It is also widely used in various other academic disciplines

including health and social sciences (Charlick et al., 2016; Smith et al., 2009; Tuffour, 2017) as well as education and humanities (Smith, 2017).

2.2.3 Theoretical Assumptions of IPA

The three major theoretical underpinnings of IPA are phenomenology, hermeneutics and idiography (Charlick et al., 2016; Larkin, Watts, & Clifton, 2006; Oxley, 2016; Smith et al., 2009; Smith & Osborn, 2004). Phenomenology is concerned with studying experience, hermeneutics is concerned with interpretation, and idiography is concerned with the nature of particular accounts (Oxley, 2016; Smith et al., 2009).

Phenomenology

First, phenomenology greatly influences IPA as it is a philosophical approach to studying lived experiences (Smith et al., 2009). The founding philosopher of phenomenology, Edmund Husserl argued that "experience should be examined in the way that it occurs in its own terms (Smith et al., 2009, p. 12). Thus, IPA requires the researcher to understand the lifeworld of the participants. However, this approach also recognises that the researcher has to interpret these experiences in order to gain in-depth understanding and make sense of the participant's actions (Smith et al., 2009; Smith & Osborn, 2004).

Hermeneutics

Hermeneutics is the theory that concerns interpretation. It is the second major theoretical underpinning of IPA (Smith et al., 2009). The interpretative requirement of IPA requires the researcher to makes sense of the concerns of the participants as well as to give detailed accounts of these interpretations. IPA researchers capture the concerns of their participants, reflect on these concerns, while also making sense of the participants' own 'making sense' of their concerns. In making sense of these concerns, the researcher offers their interpretation(s) (Larkin & Thompson, 2012; Smith et al., 2009). Hermeneutics, in this regard is a double where both the researcher and the participant are involved in sense making and interpretations, and where -the researcher is trying to understand the viewpoint from the participant's perspective (Smith & Osborn, 2004). This theoretical underpinning of IPA was a very important aspect in this study as the researcher brings herself to it as a non-disabled woman who seeks to explore and

understand the concerns of disabled women: particularly the views and experiences of daily life for these women. However, the process of the researcher exploring and making sense of the lived experiences of her participants exposes the researcher to the effects of ableism. This point will be discussed later in this chapter.

Idiography

IPA is idiographic (Smith et al., 2009; Smith & Osborn, 2004) in that it is concerned with detailed accounts of individual cases of each participant. Here, IPA can successfully be used when the study includes a small participant sample (Smith & Osborn, 2004) along with the success that IPA has in giving a voice to its participants (Larkin & Thompson, 2012). This third theoretical underpinning of IPA matched the current study as it relates well to the goal of this study, which is to 'give voice' to 'women with disabilities'. This is also in keeping with an approach that other disability studies have used in research, one that puts the voices of disabled people in the centre of the research process and product (Campbell & Oliver, 1996; Oliver, 1990).

2.2.4 How IPA works

Initially, a participant reflects on a significant event or events in their life, then shares the experience with the researcher who, in turn, interprets the event/(s) in order to understand them and their connections fully (Smith et al., 2009). This idea has been adopted by researchers in other disciplines and IPA is now used to study a wide range of topics (Smith et al., 2009). Examples of the method used by researchers within an IPA framework that provided examples for use of IPA in/for this study are briefly outlined below.

2.2.5 How IPA is used in other academic areas

In a recent study on midwifery by Charlick et al. (2016) in Australia, Samantha Charlick conducted an IPA study with the aim to explore the experiences of breastfeeding mothers "towards exclusive breastfeeding between two and six months postnatal" (p. 209). The researcher used a case study approach with a first-time mother as an exploratory method that helped her formulate and shape her interview questions. These questions were then used in a semi-structured interview format. Charlick had an idiographic focus throughout the whole process

(Charlick et al., 2016). The researcher later interviewed five mothers and explored recurring topics she developed from the case study in order to understand their stories (Charlick et al., 2016). In the final stage, Charlick read and reread the interview transcripts to develop emerging themes and identify patterns across the cases. The findings from this study revealed that by "capturing context specific situations, IPA allows broad based knowledge to be contextualised within a social and cultural context" (Charlick et al., 2016, p. 205). Charlick was able to understand the needs and issues of her participants as well as what was significant in their lives and how they made sense of their experiences (Charlick et al., 2016). The small participant sample was an advantage for Charlick to gather deeper insights.

In another study in the UK, by Bramley and Eatough (2005), three semi-structured interviews were used with one participant to explore the "lived experiences of an individual with a chronic degenerative disorder" (p. 223). The aim was to explore experiences of living with Parkinson's disease (PD). The purpose of the three interviews was to investigate a specific area of the disease. Through this process the participant freely and naturally revealed her experiences of living with PD. The manner the IPA approach was employed and analysed by Smith (1999) was used to analyse the data (Bramley & Eatough, 2005). The researchers developed a list of emergent themes arising from the data, connected the themes, and clustered them under appropriate related sub headings (Bramley & Eatough, 2005).

In this case, the participant's account is well represented and the information that was gathered is appropriately represented reflecting the most significant moments of the participant's narrative (Bramley & Eatough, 2005). The idiographic focus in this study "facilitated insight into how living with PD engenders a complex relationship between mind and body, and has a profound effect on the sense of self" (Bramley & Eatough, 2005, p. 234). The findings of this study demonstrated "the need to broaden PD patient care in order to develop disease management skills" (Bramley & Eatough, 2005, p. 234). In a way the findings can help influence policy and structure on how to assist those living with PD.

A third study by Smith et al. (2006) explored experiences of Juvenile Huntington's Disease (JHD). The researchers used semi structured interviews to

explore experiences of parents of children who had HD, and then later analysed the data using IPA (Smith et al., 2006). The aim of the study was to understand how the parents perceived JHD. The same authors emphasised that the focus of IPA to gather in-depth experiences on a particular phenomenon well suits "novel areas" (p. 487) that need to be investigated in research, for instance JHD (Smith et al., 2006). When using IPA, researchers "deal with significant, life-transforming, or -threatening events, conditions, or decisions" (Smith et al., 2006, p. 487). IPA was considered highly suitable for the research topic as "living with, and witnessing a child living with, JHD are clearly emotionally laden experiences" (Smith et al., 2006, p. 487). The researchers were able to gather in-depth, rich, and detailed descriptions of the challenges and experiences of the individual parents of the children with HD. Again, emergent themes were documented from the notes which initially captured the experiences of the parents. In the next stage the authors compared "over-arching themes for each interview and producing a table of initial comparative themes" (Smith et al., 2006, p. 488). They followed the same analysis process for the remaining number of interviews. In the final part of the analysis, the researchers compiled "a master table of comparative themes" (Smith et al., 2006, p. 488) which was used as an underlying foundation to write up the results of the study. Information from the table was later used to construct participants' narratives. The participant's quotes were embedded in the narratives (Smith et al., 2006). The use of participant's quotes in their narratives was an effective way to present their voices (which is of value when researching lived experiences).

In this research too, findings from the study revealed that the use of IPA was proven to be a useful approach in the study (Smith et al., 2006) as it provided a way for the researchers to gather rich detailed accounts of JHD from the perspective of the parents. The findings for the research will help health professionals in two ways: first, to recognise JHD symptoms from what the parents have shared and second, to conduct awareness on the impact of JHD symptoms on children. This will ensure that better support is provided for the families.

Finally, the most recent IPA study conducted by Groves, Rayner, and Muncer (2018) used semi structured interviews to explore the identities of eight women

who were living with Down syndrome (DS). Data was later analysed using IPA. Transcripts from the interviews were analysed using the steps outlined by Smith et al. (2009). IPA was deemed an appropriate methodology as it aims to explore lived experiences (Groves et al., 2018; Smith et al., 2009). The study facilitated insights into the specific events of each women's life. The findings from this study revealed that each of these women have had "numerous negative and stigmatizing experiences throughout their lives" (Groves et al., 2018, p. 451). These authors concluded that, by studying lived experiences, researchers are able to understand how people experience specific events throughout their lives (Groves et al., 2018).

The above four studies used IPA as a qualitative research tool to examine the lived experiences of participants (Bramley & Eatough, 2005; Charlick et al., 2016; Groves et al., 2018; Smith et al., 2006). Using IPA provided the means whereby researchers could commit to examining experiences on their own terms (Smith et al., 2009). In these studies, IPA was a useful tool to examine lived experiences that allowed researchers to gain deep insights into the day-to-day realities experienced by the participants. Researchers used small samples of participants, and each study took an idiographic focus which enabled the researchers to capture the concerns of the individual participants (Charlick et al., 2016). The process enabled them to interpret and understand the experiences of the participants.

The context in which this study is located takes a social model approach to working with disabled people-which the conditions of their lives are affected by societal factors more so than their own physical limitations. An IPA methodological format was chosen as the best way to find out what was happening for women with disabilities in PNG. As the literature review revealed, because of societal norms and cultural traditions, these women continue to remain silent (Spratt, 2013). Thus using a methodology that would give them a voice as much as possible in a research study was important. The "phenomenological requirement to understand and 'give voice' to the concerns of participants; and the interpretative requirement to conceptualise and make sense of these claims and concerns" (Larkin et al., 2006, p. 1) aligns well with the aim of this research project. Semi structured interviews facilitating a greater insights with women living with visible physical disabilities in PNG was envisaged to help the

researcher gain deeper understanding of their day to day realities (Cohen, Manion, & Morrison, 2011; Mutch, 2013) and enabled a more detailed interpretation of their experiences (Larkin et al., 2006).

Finally, IPA framework aligned well with this study as it "it offers a methodological approach that considers the individual in a local context. By capturing context specific situations, IPA allows broad-based knowledge to be contextualized within a social and cultural context, producing relevant findings" (Charlick et al., 2016, p. 205). The three theoretical assumptions of IPA: phenomenology, hermeneutics and idiography – enabled rich data to be captured from the participants. Their narratives are reproduced in Chapter Four.

2.3 Ableism

The final section of this chapter includes some discussion about ableism. Ableism is "a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one's body and one's relationship with others of humanity…" (Wolbring, 2008, pp. 252-253). This perception reflects an overriding societal preference for those who have "normative abilities" (Wolbring, 2008, p. 253) or are able bodied. Although 'disability' is tolerated, all people regardless of their positions are "shaped and formed by the politics of ableism" (Campbell, 2008, p. 151). As such, women with disabilities are affected by ableism (Campbell, 2008). This is due to how (non-disabled) others perceive or judge them (Wolbring, 2008) . The presence of ableism means that challenging negative views and perceptions towards people who are disabled will be difficult. This is because the perceptions and attitudes towards disability are socially constructed (Oliver, 1990; Shakespeare, 2014) as well as "culturally and economically constructed" (Campbell, 2008, p. 152). Thus these views have great power. However, ableism is also something disabled people have internalised (Campbell, 2008) and the lives of participants in this study will have been affected by these ideas.

Campbell (2009), suggests that it is important to "concentrate on what the study of disability tells us about the production, operation and maintenance of ableism" (as cited in Ellis, 2010, pp. 638-639). This became an important point for this thesis. As a non-disabled researcher studying the lives of disabled women, it became

necessary for me to include ideas about the effects of ableism since the working of ableism influenced how I, as a non-disabled woman, present the life-world of the disabled women's narratives I gathered. I return to this point in the final chapter of the thesis.

2.4 Summary of the Chapter

The chapter has provided a rationale for the use of IPA —the conceptual framework used for this study— by outlining the major theoretical underpinnings which I used to examine the views and lived experiences of women with visible, physical disabilities in a rural setting in PNG. Definitions for important terms that will be reoccurring in following chapters were provided. Then a contrast explaining the differences between the medical and social models of disability was presented. Following the discussion on the medical and social model of disability is the discussion on how IPA functions and through the studies cited from other researchers who have successfully used IPA. Justification has been provided as to why IPA is the most suitable vector to conduct this study with. Following the discussion of IPA, was the definition of ableism and its effects, influences, and relevance to this study as it has been conducted from a non-disabled woman researching the lives of disabled women.

CHAPTER THREE

RESEARCH METHODOLOGY AND METHOD

3.1 Chapter Overview

The first section of this chapter discusses the qualitative approach used as the methodology used in this study. A brief summary of the theoretical framework that guided this study is then provided. The second next section explains the reliability and validity of this research, followed by the participant demography, the ethical considerations made for this research and the method used to gather the narratives. It also discusses the process of the fieldwork, and the data analysis procedure used in this study. A concluding summary ends the chapter.

3.2 Methodology

Research is defined research as the conduct of an investigation or enquiry made in an orderly or systematic manner in which the results are made available to an audience (Menter et al., 2011). Creswell (2014) further defines qualitative research as an approach adopted by researchers in order to understand "the meaning individuals or groups ascribe to a social or human problem" (p. 4). Researchers "who engage in this form of inquiry support a way of looking at research that honours an inductive style, a focus on individual meaning, and the importance of rendering the complexity of a situation" (Creswell, 2014, p. 4). In general, a qualitative research process "involves emerging questions and procedures, data typically collected in the participant setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data" (Creswell, 2014, p. 4). Data is reduced so that research information becomes relevant and understandable to a wide range of audiences (Mutch, 2013). Information is put into a final written report, which has a flexible structure.

A qualitative research design sets the foundation for this research as well as the research question (Punch, 2005; Smith, 1999; Smith & Osborn, 2004). At the core of this study are the five semi-structured interviews conducted with five individual PNG women who have visible, physical disabilities. The interviews used were exploratory and facilitated the collection of accounts about the views and experiences that the women themselves chose to tell. An idiographic focus

was adopted throughout the research to complement the qualitative research design (Charlick et al., 2016; Smith et al., 2009).

3.2.1 Theoretical Framework

Various theoretical frameworks offer different perspectives on an issue of study. According to Crotty (1998), a theoretical perspective is "the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria" (p. 3). In the case of this study, an Interpretative Phenomenological Analysis (IPA) was used (see Chapter Two). The theoretical stance underlying this conceptual approach is interpretivism (Crotty, 1998), an idea that "emerged in contradistinction to positivism in an attempt to understand and explain human and social reality" (Crotty, 1998, pp. 66-67). The interpretivist approach taken to this study allowed me to "look for culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p. 67) of the participants.

3.3 Reliability and validity

Reliability refers to the aspect of a study where the data collected provides results which relate to the research topic and focus (Mutch, 2013). Validity in qualitative research concerns the interpretation of the data—whether or not the inferences, the researcher makes are supported by the data gathered and the findings made (Silverman, 2016). In the case of this research, validity refers to the interview transcripts that were transcribed in Tok Pisin and later translated into English. I return to this later in the chapter.

Another factor related to reliability/validity for this particular study was of IPA and how best to represent what the participants' stories told me and how to make them meaningful for the audience for this research. I had to translate the stories, yet at the same time keep the voices of my participants authentic, and maintain the meaning of their stories. In doing so, I was making sense of the participants reflections on experiences during significant moments in their lives (Eatough & Smith, 2008; Smith et al., 2009). I am aware that different people have different ways of interpreting stories and that other people can interpret the stories of my participants differently. In IPA, such interpretation is expected. It is attention paid to the authenticity of the stories themselves that provides for their validity (Mutch,

2013; Pietkiewicz & Smith, 2014; Smith et al., 2009). In addition to IPA, I incorporated a qualitative method as it linked well to the research paradigm I chose (Menter et al., 2011). Semi-structured interviews were used to provide insights from the participants' views and experiences. This helped provide better understanding of the existing phenomena (Mutch, 2013; Yoo, 2014). The overarching question which guided this research is:

> **What are the views and experiences of daily life for women living with visible, physical disabilities in Papua New Guinea?**

3.4 Demography of the participants

The physical location of my data collection phase was one of the least developed provinces in PNG. There were difficulties to reaching the research participants quickly because of poor transport services, poor road conditions, and difficulty with communication systems. Not everyone in PNG has a mobile phone, access to the internet, or a physical mailing address. In PNG, specifically my data collection site, the most efficient and widely used form of communication in local communities is passing of information from one person to another. As previously indicated, the contact person has informally agreed to act as liaison (contact person) and has ensured that the information she shares with me about the participants will remain confidential.

3.4.1 Communication Problem

The day I arrived in Port Moresby, the capital city of PNG, I was not able to communicate with the contact person and inform her of my arrival in the country because of network issues. Communication was an issue for almost a week when I arrived at the data collection area. I was not able to email the contact person, call or message her by phone. This was because of the remoteness of the location. I had to create a plan for myself. I took the bus to where she was located and met her by surprise. At my first meeting with the contact person, she gave me a list of initial participants and we discussed where and how to reach each participant and where they lived. After she signed the confidentiality form (see Appendix C), she helped me to send word to notify the participants, gave me their names, and when or where to contact if I needed to see them.

3.5 Ethical Consideration

As I was to work with a specific group of people who are considered vulnerable, how I was to protect my participants ethically was a very important aspect of the research focus. This study complies with Ethical Conduct in Human Research and Related Activities and Regulations at the University of Waikato (2008). I sought Ethics Approval from the School of Education Ethics Committee. The ethics application was returned after submission because I was required to be consistent with what I stated on my ethics application and the letters to the participants. I was required to state the title of my research project on all appendices in the same way. I also had to discuss anonymity of participants. The research proposal was approved after making this slight amendment on the ethics application (see Appendix A).

The ethical considerations of my research project included the required information about my research project outlined and discussed very clearly. This included information on a number of matters listed below.

- The research topic;
- The ethics application submission; my name and contact details both in NZ and PNG; my programme of study, my supervisor's name and contact details; the course number for the paper I am currently enrolled in; my current qualification and the title of my research topic;
- A summary discussion of my interest in this research topic which included:
    - Justification to why I chose the research topic;
    - Procedures for recruiting participants;
    - Procedures in which participants will be involved in; and
    - Procedures for handling information and materials; produced in the course of the research
- I also discussed:
    - How I will have access to participants;
    - How participants will give consent;
    - How I will maintain anonymity and confidentiality;

- How to minimise potential harm to the participants and myself, and if there was any, the process and procedures that will be involved;
- Participants' right to decline/ withdraw from participation and withdraw data;
- The arrangements for participants to receive information
- The use of information in terms of permission from participants to use their stories in my publications and presentations;
- Procedures for resolution of disputes if there was any; and
- Cultural and social considerations

I outlined clearly the legal ownership of the thesis and information and the data analysis discussion. I provided a research time table to the Ethics Committee and finally, an Ethics Application Agreement was completed and signed by my supervisor and myself.

3.5.1 Access to Participants /Participant Selection

It was not easy to gain access to my participants from New Zealand, so I made contact with a former colleague who currently works at a Special Education Resource Centre (SERC) in PNG. The SERC provides basic services to disabled people. I enlisted the assistance of my contact person, to act as liaison, between myself and the women with visible, physical disabilities (see Appendix B). The communication between the contact person and me was via email. The information about the research (see Appendix D) and the recruitment criteria (see Appendix E) were emailed to her. The contact person has a database of existing members who met my criteria for this research. Going through the database, she selected suitable women capable of sharing their thoughts and insights with me. The contact person then met and discussed the information with those who are not able to understand verbal and written English in Tok Pisin—a common language widely understood by most people in PNG. Thanks to my contact person, I was able to identify initial participants. The contact person had to sign a confidentiality agreement to ensure that highest level of confidentiality was maintained with regards to her involvement in this part of the research and not

disclose any information pertaining to her contribution to the study (see Appendix C). This was done when I arrived in PNG. She continued to act as a liaison between the participants and myself during my data gathering time in PNG.

3.5.2 Insider Researcher

The fieldwork was conducted in a setting which I was familiar with in terms of the lifestyle and situation of the place. Throughout I endeavoured to maintain my stance as a researcher, as a co-learner, and as a fellow PNG woman. The major difference between my participants and me is that they are disabled while I am not. This was one of my greatest concerns throughout the research process. It was clear that I am non-disabled, educated, and able to speak and write in English. This put me in a hierarchical position over them in this rural setting. I carried my bag pack with my laptop, with my pen, journal, my voice recorder and a phone. This also put me in a position of difference (Sultana, 2007). However, the way I dressed (a pair of pants and blouse), the footwear I wore (a pair of thongs), and how I approached my participants positioned me as an insider, as a woman from a rural setting.

I was also aware of the limitations of my participants and allowed time for that. For example, there were times we arranged to meet at a convenient spot of their choice and time, but they did not show up on time or did not make it to the venue. Being aware of the limitations surrounding them, at times I would travel on the bus, get off and walk to where they live and check at their houses whether they were well and were comfortable to meet up for the interview at another time. I understood what it means to have patience at a deeper level as I had to wait for the convenient time when my participants were comfortable, willing and ready to share their stories.

3.5.3 Participants

The participants of this study were five young adult women with visible, physical disabilities from the ages of 16 to 35 years. The selection was narrowed to this group because I wanted to examine their experiences of navigating their way around their local rural community and the commonalities and differences. Meeting with the participants face to face was a difficult situation for me. Although I was familiar with the situation of the lifestyle, situation, and

environment of the place, it was still difficult to reach each participant at the time I had planned. The table below shows the names and ages of the participants.

Table 1: Name (pseudonyms) and age of participants

Participant	Age
1. Angie	32
2. Essie	24
3. Rebecca	16
4. Gee	28
5. Amber	35

3.5.3.1 Meeting the Participants

Angie happened to travel into town the same day I met the contact person, so she was informed by the contact person that I was already at the data collection site and needed to speak to her. I met her the next day and spoke to her about my research. She was happy and willing to participate so she happened to be the first person to be interviewed. We did the interview on the following day, as she was travelling back to the village in few days' time. The interview with Angie was the longest of all the interviews. Angie felt free to share her story with me which revealed many interesting themes.

Essie was the second person I arranged to meet with. Due to communication difficulties, we did not meet until two weeks later. During that time, I learnt to be patient. The first time we arranged to meet, she did not turn up, so I had to visit her at her home and arrange a convenient time to meet her. At the time of the interview she was excited that she had the chance to come out of her home (also discussed in Essie's Chapter Four reflection).

Rebecca was the third participant I met. She was happy when she heard that I wanted to see her and we met without difficulty. When we met and talked about the interview she was pleased to be interviewed. During the introduction, Rebecca introduced herself and told me she was sixteen years old. At that instant, I realised she was not in the age category of 18-35, the age group which I gained approval from the ethics committee to interview. Ethically, it was not right to stop her from proceeding with the interview, so we followed all the steps required, she gave

consent to be interviewed and we proceeded with the interview. After the interview, I thanked and gave her a thank you gift as I did with the other participants. After the interview I emailed my supervisor and informed her that I had already interviewed a 16-year-old and explained that it was not appropriate to tell her to stop and not do the interview with her when she came prepared for the interview. My supervisor advised me to keep the information, to inform the ethics committee when I return. Upon returning to the University, I discussed this with my supervisor, I wrote a memo to the Ethics Committee explaining the situation and requested retrospective approval from the committee to include the information of the 16-year-old participant (see Appendix J). The University Ethics Committee granted the retrospective approval and I included the 16-year-old participant in my research thesis (see Appendix K).

Gee was happy to be interviewed. However at the time of the interview, she did not arrive on time at the venue location, so I had to go and check on her to see if she was alright. When we arranged a second time to meet, she was not around at the venue. At that time, I had to go and check where she was, and found her admitted at the hospital because she was very sick with malaria. We arranged to meet a week after, which worked out (see Chapter 4).

Amber was the last participant interviewed. Two previous attempts for meeting up with Amber failed. When I first met with Amber and spoke about my research, she was happy and willing to be interviewed. However, when we arranged to meet for the interview, she did not turn up because her son was sick and she was admitted at the hospital with him. Two weeks later, we made a second arrangement to meet for the interview. This second arrangement did not work out as Amber had to go to the hospital to deliver her second child. I went to the hospital to check and found she was discharged. When we finally met for the interview, she was happy and we did the interview.

3.5.4 Pre-interview consent

At our first meeting, I provided an information sheet (see Appendix F) and offered further explanation of who I am and what their involvement in my research would entail. Participants were reminded that participation was voluntary, that they had the right to decline to participate, and, they had the absolute right to withdraw

from my research until I the data analysis process has commenced with them (Burns, 2000; Mutch, 2013). I then asked if they wanted to go ahead with the interview. Upon agreement, I provided the initial invitation letter (see Appendix G), and discussed it. We then arranged a suitable day, time, and venue.

3.5.5 Interview Day

Before the interviews took place, I asked each participant if they had any questions which needed clarification. After that I had them give their consent by signing the consent form (see Appendix H). For those who were not able to read or write, I sought their verbal consent using the words "I, X agree to participate in Alice Yenas' study" which was digitally recorded as evidence or by an X marked on their consent form. At that time, I mentioned also that, should they wish to review their transcripts, a further meeting would be arranged giving them time to read and check their transcripts or a summary thereof. For those who were unable to read and write, I offered to read through the transcripts with them or provide a verbal summary. None of the participants wanted to go through the transcripts but agreed that I should provide a summary of what they shared with me after my study.

3.6 Method

3.6.1 Interviews

Interviews are suitable in situations where researchers seek to understand the lived experiences of people, explore what is happening in and around the participants' worlds, and to understand people from different perspectives. Through interviews, participants can share their lived experiences, giving researchers a window into their lives and the opportunity to understand how the participants achieve things, and why they think differently in different situations. Researchers also develop an understanding of why certain methods work for some individuals and/ or groups and not others. Interviews provide rich data or qualitative knowledge and allow researchers to explore the participant's world, draw from specific situations, and develop new knowledge (Kvale & Brinkmann, 2009).

Semi-structured interviews were chosen to help me gain deeper understanding of day-to-day realities (Cohen et al., 2011; Mutch, 2013) of women living with visible, physical disabilities in PNG which would enable me to provide detailed

interpretations of participants' experiences (Larkin et al., 2006). Comprehensive accounts on the views and experiences of daily life for each participant are provided with my own interpretation, and analysis of each participant's narrative in a separate chapter of this thesis (see Chapter Four).

Three of the five interviews were conducted on the floor of a house, the participants and I sat on a mat that was spread on the floor. Two other interviews were conducted on locally made seats in a rest house (*haus win*). The participants were comfortable with that throughout the research process. In all the interviews our sitting positions were the same. The participants and I either sat on the floor together, or on the seats in the rest house. Our sitting positions did not establish any power difference however, the sitting positions allowed us to have a good dialogue. Throughout the interviews, the participants were comfortable talking to me in that position. I was aware that sensitive stories could arise during the interview process that could bring back sad, painful, or stressful memories for the interviewees. I tried to avoid language that may create stress. I was also mindful of my words and actions.

I was also flexible with my participants as I am aware that my participants have limitations. I learnt patience during the times we arranged to meet and they did not show up at that time and venue.

3.6.2 Cultural and social considerations

In various cultures in PNG, sometimes the deepest pains, wounds and damages are hidden and kept secret to protect the good name of the village, clan or very society. My participants were also aware of these cultural practices, and this guided what they felt comfortable sharing. The participants were also informed that there were some questions or topics which may be upsetting or sensitive and they had the right to pause or stop. When details of their private lives are discussed, which would need "sufficient level of trust" (Creswell, 2002, p. 230), the information discussed would remain confidential but if there was any disclosure of any information that could possibly lead to harm, or if there was something that is causing harm I advised them to seek counselling.

3.6.3 Cultivating trust and establishing rapport

I believe that by establishing trust and rapport in the way that I did, and in creating the safe space for them, the women felt supported and empowered which enabled them to share their stories. In this way, their stories became my stories and as I place them in this thesis, these stories become accessible to everyone. Here, I acknowledge the stories each of these women have shared with me about their daily lives. In my Master's thesis journey, these stories have become "legitimate sources of knowledge" (Campbell & Wasco, 2000, p. 778) and I hope to suggest ways to empower and improve some situations in their lives.

3.6.4 Translation

All the interviews were conducted in Tok Pisin which is the language, most commonly spoken and understood by myself and the research participants. I transcribed the all the interviews verbatim in Pidgin and later translated the pidgin transcriptions to English. During the translation I made sure to capture the essence of the words of my participants as much as possible as my aim was to capture their voices as well as make meaning of what they shared. For example,

In Tok Pisin, Gee said:

…planti taim... mi no sa sindaun gud... (Gee)

Literal translation:

…many times…I do not sit well… (Gee)

English translation: (Making sense of what Gee said)

…life is not always easy… (Gee)

Here, Gee's words do not literally mean that she does not sit well, what she meant was, her life is not always easy. I had to totally immerse myself in the words that Gee had spoken in order to capture the essence of her words (Pietkiewicz & Smith, 2014).

3.6.5 Anonymity and Confidentiality

The privacy of the participants are protected by maintaining as high a level of confidentiality as possible (Cohen et al., 2011). Throughout the thesis writing process, and in any presentations and publications, anonymity and confidentiality

of all these participants are protected by the use of pseudonyms (Cohen et al., 2011; Mutch, 2013). Also in future presentations and publications they will remain anonymous (Cohen, Manion, & Morrison, 2000). This aspect of the ethical part of research is important, because the female participants who are involved are concerned about their safety after the interviews are conducted and they have shared their information.

3.6.6 Potential harm to participants

The research has been organised to minimise, as much as possible, the level of harm to participants who agree to share their experiences. I discussed with my participants that if they needed help they could go to the Counselling Office in the XXX area. I provided details for them of where to go if they needed counselling or if they needed to talk to anyone in that office. Although I provided the information, none of my participants sought assistance from the counselling office.

3.6.7 Participants' right to decline/ withdraw and withdraw data

Participants were informed that they had an absolute right to decline, to participate, or to withdraw from the study at any time. During my initial contact and throughout the interview process, I assured the participants that they can withdraw at any time up until their transcripts have been checked for accuracy.

3.6.8 Arrangements for participants to receive information

Information about this part of research was included in the consent form. Before the interview started, I went through the details about the research project. I made it clear that findings from the study will be provided to the participants. I will have time to discuss findings of my study with them. Though some of these women may not be able to read my thesis, I will still show my completed work and discuss my findings with them through a short presentation.

3.6.9 Use of the information

The participants gave me their permission to use their stories for the research project through the consent form and/or the verbal consent which was digitally recorded.

3.7 Field Work

3.7.1 Structure of my field work

In this study, I was required to travel in person to the physical location of my participants in order to conduct face-to-face interviews and collect the data for my study. This study's participants live in a rural and remote area of one of the 22 provinces of PNG, therefore the data gathered is influenced by the isolated setting. This setting was chosen because it is both relevant to, and appropriate for the research question and the focus of this study.

Due to the nature of the setting and the province I visited being the least developed in PNG, a country which itself is a developing nation (Aisi, 2014), recruiting participants from this rural area was a challenging experience. Factors such as poor communication systems, difficult accessibility because of terrain, and poor road conditions added to the difficulty in acquiring data. However, the difficulties of the journey only added to the experience and aided me in understanding the situation for the research participants and the information I gathered.

3.7.2 Plan for the study

The procedure employed to collect data for this study consisted of a number of stages: preparation and research approval; field work and data collection; data analysis and interpretation; and finally, summarisation and making conclusions. The process required the researcher to make decisions that would ensure effective data collection and that would not hinder the data collection process. The researcher made sure that each step of the process acquired adequate data to save time, effort and external resources like funding. For example, at the times when the participants did not arrive for the interview, the researcher had to physically visit the participant and arrange a convenient time and venue.

In my ethics application I stated that I would need only four participants for my research and I stated clearly what is required of me and how I would go about this (See section 3.5). My ethics application process had the information about only four participants, for which I was given approval. However, during the data gathering process, a 16-year-old participant arrived for an interview and was happy to be interviewed. During the introduction, she introduced herself and told

me that she was 16 years, outside the age range of my ethical approval. We proceeded with the interview. Then, through my supervisor, after I return to New Zealand, I applied for retrospective approval from the Ethics Committee. This was granted so my data analysis for this study is based on information from five women and not four, as I have previously indicated.

3.7.3 Communication with Supervisor

I maintained communication with my supervisor during the time of research. During the research process, the approach discussed by (Mutch, 2013)was taken into consideration by taking care of myself and not putting myself in a position of distress, either physical or emotional. Throughout the data collection period I communicated with my supervisor.

3.8 Reflexivity

In this research, I worked to create a non-hierarchical relationship between myself and the participants (Oakley, 1998 as cited in Gee, 2016). Through this process, there was space for interaction and participants were able to share their personal experiences of significant moments in their life's journey. Knowledge was obtained and constructed by "virtue of the interaction of the knower with [the] already known and the still-knowable or to be-known" (Guba & Lincoln, 1989 as cited in Gee, 2016, p. 48) and I became a learner as well as the participants in order to discover, gain knowledge and develop an understanding about their life-worlds (Gee, 2016).

According to Yin, (2011, as cited in Gee, 2016),

> Qualitative researchers have both a reflective and declarative self. By presenting the reflective self, the researcher becomes aware and explicit about his or her values, beliefs, motives and background as these impact on the construction of knowledge and the assumptions made about data interpretation. This also helps to avoid potential bias and idiosyncrasies during data selection and interpretation. (p. 49)

Conducting a study in a site I was familiar with, brought in the dimensions of the concerns of insider-outsider perspective (Sultana, 2007). I was an insider as a woman from the same community as my participants, who share commonalities. However, my participants are disabled women while I am able bodied.

3.9 Analysis of the Interviews

In every research process, researchers are required to collect, analyse and interpret the data that has been gathered (Mutch, 2013). Qualitative data analysis "requires understanding how to make sense of texts …that can form answers to research questions" (Creswell, 2005, p. 230). In this study, the information that was provided by the participants was developed into in-depth analysis where the cases were written as narratives. This happens when researchers use selected processes and procedure to collect and analyse data with possible findings and offer possible suggestions that could improve existing practices (Tomal & Hastert, 2010 as cited in Bomen, 2017).

According to (Smith et al., 2009)

> Data collection is usually (but not necessarily) in the form of semi-structured interviews where an interview schedule is …covered. Transcripts of interviews are analysed case by case through a systematic, qualitative analysis. This is then turned into a narrative account where the researcher's analytic interpretation is presented in detail and is supported with verbatim extracts from participants. (p. 4)

3.9.1 Data analysis and interpretation

IPA researchers are encouraged to be creative and innovative when analysing data (Smith et al., 2009). The analysis of data in this research was conducted in several stages to achieve results that are valid and trustworthy. As much as possible, I made sure the results I present are authentic, as my aim was to capture the essence of the participants' voice and make meaning of their experiences.

I transcribed the five interviews verbatim in PNG Tok Pisin and then translated them to English. Step 1 and Step 2 enabled me to familiarise myself with the data. I also made notes during the process of translating the scripts from Tok Pisin to English, at the same time making meaning of the participants words and refining the wording of my translations. Firstly, I read and re-read the transcript several times to capture the essence of the participant. Secondly, I noted and highlighted important points from the texts. I then used the English scripts to develop participants' narratives as single cases. I started the process with Angie's transcript and followed the same process for the other four participants. Rich

complex narratives were uncovered during the process of developing participants' life stories/ narratives (Gibson, 2012; Hamilton & Atkinson, 2009). From there, I compiled the narratives of each participant placing my own reflections at the end of the narratives (Gee, 2016). The narrative development included a brief background of each participant, their personal stories, which included the participants own voice (direct quotes) on their views and experiences of daily life, and my reflection at the end of each narrative. This was done to provide an evidence of what the participants actually said, regarding the phenomenon being investigated (Pietkiewicz & Smith, 2014). During the process of developing Angie's narrative, I was deeply immersed in the data I gathered. I found this process stressful as I developed the first narrative account. Angie's story is full of very difficult experiences, which is rich and in-depth, and I was seeing her story from her perspective. As a result, I was emotionally distracted during the process of developing her story. After that, all the other narratives were developed. This process also helped me make sense of the participants of the participants' reflections on the significant moments in their life. The use of participants' extracts also helped me to make sure I provided accurate interpretations of the participants' words according to IPA because IPA aims to purely describe a lived experience without attempting to give meaning to it (Charlick et al., 2016; Smith et al., 2009).

3.9.2 Developing superordinate theme areas

To develop the theme areas identified in Chapter Five, I initially identified emergent themes. From the narratives I was able to make descriptive comments on what the participants mentioned and I provided interpretations for those comments. From the narratives I searched, made notes, and coded the themes that emerged from the narratives using coloured pens and highlighters. In this process, I noted each theme and added the participant's extracts on particular themes.

Step 2 involved searching for connections across the emergent themes. From these connections superordinate themes were developed. The superordinate themes were organised in a table. I also listed the constituent themes next to their superordinate themes. Looking for emergent themes across all the participants' narratives and making those connections broadened my understanding of the commonalities and differences in the experiences of my participants. Though the

process was time consuming, it was an interesting journey as it provided a way for me to gather detailed accounts of the participants. I then looked for patterns across the cases and noted the common themes, themes that were connected, and themes that differed.

Step 3 and Step 4 were done together. This was reiterating the previous steps and following what had been done on Angie's case for the other four participants. The same salient and superordinate themes that had been identified and developed for Angie's case were recycled for the other four cases, Essie, Rebecca, Gee and Amber. I noted what was said by the other participants that related to the superordinate themes that I developed. At this stage I also noted what the participants mentioned, which was not common in the other interviews. I noted the point and made a comment next to it, discussing that in relation to its uniqueness as well as the significance of addressing it. For example, Angie's story revealed how she was most affected in terms of abuse. She experienced more abuse than the other participants and I noted that I should discuss this. When I started, the case of each participant looked incomplete, as I needed to include more information, as the constituent themes underlying the superordinate themes were interconnected. This made the process difficult and complicated. The parts developed together as I had to revisit the narratives repeatedly to get the actual quote the participant made on particular constituent themes (Jeong & Othman, 2016). Again, this helped me to deeply immerse myself in the data. In this stage I created a table of superordinate themes and constituent themes and made notes next to what I found. This step helped me to prepare for the writing of my findings. At this point, data from all five participants were incorporated into what I found in Angie's case at first. I made sure what I found was also relevant to my research question. I was emotional and felt depressed in the process because the narratives of the real-life events that had been shared with me included some painful memories. As a result, during the narrative development process, I was emotionally distracted at times. In describing the lived experiences of my participants, I had to immerse myself in the data they have provided in order to fully understand their lived experiences. This was evident in the process of developing the narratives of the participants. The process came about six weeks after the actual interviews took place. The narrative accounts of the participants in

this study, also known as life stories (Hamilton & Atkinson, 2009) based on their views and experiences of daily life have helped me gain deeper understanding of the lived experiences of the participants.

I felt differently when I was developing the participants' narratives from the translated scripts than when I interviewed the participants. During the interview process, I was ready to listen to the stories and gather all the information I needed as a researcher. At that time, I did not feel emotional about what the participants had told me. According to Charlick et al. (2016), "Edmund Husserl (1927)…suggested that during data collection and analysis the researcher should 'bracket,' or leave aside their previous knowledge and investments, and also the taken-for-granted world, in order to see phenomenon as experienced" (p. 206).

This is achieved by the researcher "through the process of going back to and reflecting on the phenomenon itself rather than attempting to fix experience in predefined categories (Charlick et al., 2016, p. 207). Another main influence is with bracketing, this is done when leaving aside previous case or knowledge and look at new cases (Charlick et al., 2016; Smith et al., 2009)

According Reiners (2012), Edmund Husserl's student, "Martin Heidegger (1889-1976), rejected the theory of knowledge known as epistemology, and adopted ontology, the science of being. Heidegger developed interpretive phenomenology by extending hermeneutics, the philosophy of interpretation" (p. 1). Reiners (2012) also noted that "Heidegger broadened hermeneutics by studying the concept of being in the world rather than knowing the world. Hermeneutics moves beyond the description or core concepts of the experience and seeks meanings that are embedded in everyday occurrences" (p. 5). Reiners (2012) further noted that Heidegger, who was interested in interpreting and describing human experience, believed that bracketing was not warranted because hermeneutics presumed prior understanding (p. 1). The process of bracketing as described above was used in this study because at the time of the interviews I did not feel anything about what the participants shared with me.

3.10 Summary of the Chapter

This chapter has presented a clear explanation of the theoretical framework of this qualitative study, and the research methodology that I used to enter the world of

the participants in this research. This part included the qualitative enquiry in which IPA was the qualitative research tool that was adopted in this research as it was significant to the research approach. The interpretative-constructivist paradigm was the underlying basis of this study. This qualitative inquiry was based on exploring the lived experiences of women with visible, physical disabilities. The study used the three theoretical underpinning of IPA, phenomenology, hermeneutics (also known as interpretative requirement), and idiography, as lenses to study the lives of these women. The chapter has also explained in detail the ethical considerations, the processes and procedures that were involved in carrying out this research and the data analysis process of this research.

CHAPTER FOUR

CASE STUDIES

This chapter presents the five narratives about the views and experiences of daily life for women living with visible, physical disabilities in a rural setting in PNG. Each narrative begins with a brief introduction of the woman, her family, and how her disability was acquired. How the women live and how they overcome challenges they face in their daily lives is then presented. Finally, a reflection on the salient points of each woman's narrative is included.

4.1 Case Study One: Angie

Background

Angie is 30 years old and originally from May, a small village in a province of PNG. She was born with her right leg much smaller and shorter than her left leg, and consequently her mobility has been affected since she was small. She moves around with the assistance of crutches and a wheelchair. Angie was the only child in her family. Her father left her mother when she was pregnant with Angie, so she has lived with her mother and grandmother since she was born. She does not know her father personally and does not have any father-daughter relationship with him. When her mother died she lived with her grandmother, and some years later her grandmother also died.

When Angie was 16 years old, she left her village and went to X. From X she travelled to Z and stayed there. Her brother in-law took her to stay with him and his wife, who is Angie's distant cousin. Today, Angie lives at Y. As she reveals in her story, living with her brother-in-law and his family did not work out so her brother in-law built a separate house for her. She now lives in her own house next to her cousin's family.

Angie's Story

> *I do things by myself like: fetching water, collecting greens, or growing food like bananas around the house …when I have money, I buy at the market … I sell things at the market … I make bilums,* [string bags]**...** *make sago strainer using nylon strings, and cut grass around the house …to plant peanuts, bananas or corn … I am able to scrape coconuts, …sweep … I do these things to sustain my living… I do my own cooking, I scrape the coconut* [dried] *and* [extract coconut] *milk* [from its flesh] *and prepare greens …* [independently]*… I do my own laundry…* [I] *chop firewood… I clean around the house... I conduct these* [daily chores/activities, all] *by myself.*
>
> *My greatest need is a wheel chair… I am using one now… I am used to the wheelchair, and I have been using it for a very long time…I can* [use my wheelchair] *to easily move my things for long distances … I pull it, I crawl and pull it,* [she gets on the ground to do this]*…I will either pull from the*

front or from the back, like reversing it. Then I put my things [from a bilum (bag)] *at the back of* [she hangs the bag on the wheelchair handle]*... get on it and wheel it … When I have food like bananas or peanuts, I will put them on the wheel chair and take them to the road … I balance the weight with the wheels … and then wheel the wheelchair back to the house …Water, I can carry it on the wheel chair… water and food … Even on a mountain, I can still push my wheel chair up … that is when I need force* [as] *I am scared that it might reverse back to me …*

When a car comes and stops, I give them the crutches and get on, if not, at times, the car crew will lift me up and put me on the car but I feel scared of falling and tell them to leave me so that I will get on the car, myself… I am scared that I might fall or they might let go of their hands on me. They give me space to get on and just assist by holding onto my legs … I support myself when getting off the car, other people hold my crutches and give them to me, and I put them on the ground next to car the so that they I am able to use them as soon as I get off, the other hand will support myself by holding onto the crutch. When I get off the ground I get my bilum [and] *put it on my head. If there is food, people on the car will help to put it on the ground… I travel to town* [to sell my stuff at the town market]...

I live in a different house from them…my brother in law built my house separately from his family because his wife [my cousin] *does not accept me. He took me to his family and wanted me to live with them, but his wife has ill feelings towards me so he built my own house, bit far from where their house is, they planted bananas in the space between the houses so that I can be on my own… they* [the family she lives with] *gave me some land space to make gardens that, is why I am able to plant bananas, cut grass and plant peanuts…*

[Sometimes] *they want me to remain* [at the house] *they do not want me to go out of the house* [leave the house and go somewhere]. *Sometimes they give me sago* [food]. *They have many children and the children will want to eat* [at times food will be scarce]...

Sometimes they cook very late at night and eat. In the morning they will pretend that there is no food. At this time I remind myself that God will satisfy my hunger with whatever [little] *I eat, at least I eat a banana or breadfruit seeds. I will put breadfruit seeds in an empty can of fish and roast them on open fire and cook two bananas on the fire, eat and also drink water. I only take food in the afternoons and not in the mornings…At times they tell me to move out of the house…This makes me feel so sad at heart and makes me think of committing suicide but I keep it all to myself and move around with a heavy heart...* [Sobbing].

They call me S [referring to how she walks] *like they will say S …Snail in their dialect means S and they call me S. They say I am a snail that crawls… Many people call me this name. When they are angry with me they say the way I move around is like how ducks and chickens move … they say I am not worthy… this is what I do not like… I always think of committing suicide because of this… I am wasting my time here… I feel that it is not good to degrade me* [to a level] *so low like that, if that is the case I should commit suicide… they* [tend] *to degrade me and make me feel so low because they see me as being different from them. May be they do not want to have a woman like me living with them. They want all able bodied people to live together and not a woman with disability like me to live with them. Having a woman with disability like me* [around] *brings shame to them.*

…My cousin …wanted me to go and baby sit her child while she goes to work…[but] *her father and mother said I would bring shame to her* [if I go and live with her]*… I felt that…I should be doing my own thing such as growing corns and peanuts for myself…* [When the parents said that]*… I felt so bad because they are not the same as me, I am different from them, and that is why they do not want me to go and live with their daughter… I might bring shame to their daughter because I am different… if I don't have a disability… they will accept me.*

…When people say this about me I feel that it is degrading and shameful…they do not want me to be around them, maybe I should… go

live by myself… I should go [away and] *stay by myself because abled bodied people do not accept me, they do not want me to live with them here …I should live with my group, the people with disabilities…*

At this point in this narrative, I, as the researcher enter this story because Angie shared some examples of times where she experienced abuse in her wider community. I provide some explanation of what was an extended story. First, she disclosed and incident when she was physically assaulted by someone who was drunk.

On that day, I did my laundry and went to the road side to wait to for the car [to get to town to observe the National Day for People with Disabilities]. *This man was sitting on the other side of the road, he must have smoked drugs. I sat with the mothers at the road side market …I did not see him... I stood up and looked at* [what was at] *market stall…this man looked up and accused us for staring at him, he said "You people staring at me?" He then picked up some stones and threw them at us…we missed the third throw, he walked straight at us, walked passed those who stood in front…and came straight to me at the back and hit me…*

She then told me how she was physically abused.

…. He got my crutches and was about to violently hit me on the head but I blocked it with my hand… The nut on the crutch left a bruise which became sore… He broke a bone on my leg… After he hit me, he left. There were other women in front of me but he did not do anything to them... the children that were around ran and told some people…they came and rescued me. He was angry with me [and] *he hit me because he often told me that he was interested in me but I showed no interest...*

Community members tried to help her to get to the hospital.

…There was blood on the ground and on where I was sitting, they called the ambulance but the ambulance …needed fixing so they had to find another vehicle to help get me to the hospital…on our way, the river was flooded …so we went back. I was in great pain the whole night… In the

morning, my sister carried me to a place to wait for the …car but the river was still flooding.

As a result, Angie also holds fears about intimate relationships.

> *… This young man admires me and tells me that he is interested in me but I usually …tell him that… I am different from you* [referring to her disability]. *God made you perfect and has also made a perfect match for you there. He made me disabled… I have a life to live since I was born. And he would say "sssshhh, it's just to pass the time and live",* [but] *I* [tell him] *there are women who are suitable for you around. I will* [then] *ask: What do you think?* [Is it that were are going to get married and or] *will I come and live with you or you just want to deceive to me and just use me…His response will be, "No, that's just to pass the time", and I would say… If I do this, able bodied people might see me and say "Look at her, she is not fit enough to do that. How could she carry a child and move around with it [the child]? She will have to carry a child…move around with the child and cook food…but he did not consider what I said… Once he really forced himself to my house… He kicked the door…when I screamed* [for help], [some] *villagers came and he ran away. That is why I don't feel safe moving around by myself…*

Angie also spoke about her lack of safety in places where she should have been surrounded by supportive people.

> *… When I was at the Centre with the broken bone, this person* [Someone responsible to help people with disabilities do exercise] *pushed the door of the room where I was sleeping and said he wanted to ejaculate, (Jones)… I told him I am scared, I do not want to commit sin, I am scared to go to the priest to confess my sins, the greatest thing is, it will be a shame confessing because people are going to say, she is disabled and why did she do this?, they will ask, who will take care of you, do you have a family (to look after you)?... it was in the night, everyone was asleep, he asked but I declined, no one knew what he did. He came back the second time and asked but I said No… He is not around* [now]...

I return to Angie's own narrative here.

> *They* [The women at the market] *communicate well with me, when we are together at the market, they share food with me…* [Other women with disabilities] *… communicate* [and interact] *well with me, they share …the things that they bring to the market with me.*
>
> *…At the market, I crawl and fix the things* [for sale] *…because we normally sit on the ground and put our food stuff on a plastic sheet to sell…Other women can use artificial legs while I use crutches. They can easily move around with their artificial legs in the market, if I leave* [my crutches] *I will crawl and do things. It is better for me to sit and sell rather than moving around at the crowded space in the market…*
>
> *… People with disabilities communicate well with me … …We have a good conversation* [when we are together] *they would ask if I had gone to the Centre, or heard any news from the Centre* [referring to the Special Education Resource Centre – SERC] *… They want to know if there is any form of training* [education] *or any gathering for us, people with disabilities, or if there are any games* [sporting activities/events] *for persons with disabilities... I will tell them, I haven't heard anything…as for me, I do not have money* [funds] *to support me* [in such activities] *because I often struggle a lot, because I do not have a family… you people have families to support you all so you can show your interest… As for me I am not interested...*
>
> *When I leave home, come out and meet other people with disabilities or when I am involved in some form of games or disability sport I feel happy… when I come to town and meet other people or go to the centre I feel happy. Like sitting with you now and talking, I am happy, and I appreciate this because it helps gives me space to think positively* [about myself and the things I do] *…It is good to meet and talk with others. When I am alone I* [reflect and] *feel that it was great catching up with others but when I return home I stay with the same people, same family,* [same things happening]*… these people will be wondering when I should leave them…When I go home I work to pass the time…*

Reflection

Angie lives in one of the least developed provinces of PNG, with a very low socio-economic status that has contributed to a poor standard of living for its residents. People in this rural area experience difficulties in various aspects of life including the type of services available, communication systems, roads and other types of infrastructure. The low socio-economic status of people in the area and the poor basic services have contributed to Angie's negative experiences and affected the way she lives with her disability.

Living in a community and rural setting where there is not much money is an issue for Angie. As revealed in her story, her standard of living is very poor. She mentions she has very few possessions in her home. Whatever she has, she buys with the money she earns from selling what she is able to produce. This is her only source of income. If Angie is not able to plant anything to sell, she will not have any precariosity. Although she struggles to provide for herself she is active and independent in spite of her disability. She lives the life of a woman in a rural community, not expecting assistance from anyone but persistently working hard to provide for herself and sustain her daily living.

As can be seen in her stories, the challenges Angie encounters are multiple and contribute to her experiencing stigma and other forms of discrimination. Not having complete support from an immediate family means life is incredibly difficult for her. Because Angie also comes from a patriarchal society; a society where the needs of women are subservient to that of men, she feels helpless at times and does not speak up for what she thinks is right. However, Angie's exclusion through discrimination from her community is compounded by her disability.

To a great extent, Angie carries around with her an embodied experience of abuse, stigma, and discrimination. These experiences contribute to Angie having doubts about herself and questioning her self-worth as a 'woman'. Further, there seems to be no one to speak up for her. However, her story is full of activities that she manages on her own. When she does ask for help, it is to people in the wider community, who seem the most willing to assist her. In turn, she contributes to

the community she lives in by carrying out simple activities at home and assisting others at the market.

The market is a place where Angie gets to meet other women, socialise and interact with them. She sells her produce at the market to earn some income in spite of her poor living condition as well as assisting her friends to sell produce for other friends. She does not take her challenges and negative experiences as things that will hinder, her but pushes herself to be independent and autonomous. She finds her strength also at the market as a place where she can sell her produce to earn some income in spite of her poor living condition.

As her narrative reveals, Angie has suffered repeated psychological abuse through the words, attitudes, perceptions, assumptions, views and actions of those who live close to her and from people who live in her community. She has also suffered physical abuse and assault, which has caused her to suffer great pain and to need medical assistance. She also talked at length about relationships. In particular, her story shows her fear of getting into any relationship with men. During the time of interview, Angie was going through some counselling as she was raped some time ago and the incident has affected her emotionally, psychologically and physically. She has people who are assisting her through this process, but these incidents have led her to question the motives of men who approach her. She now doubts that any man would seriously want a lifetime relationship with her. She has her own fear of being able to care for and manage a child, and she questions what the community might think of her where she had to start a relationship or to have a child.

It is clear that Angie is happiest when she leaves home and comes into town, where she meets other people and has other friends with disabilities. On these occasions, she can forget about all these negative experiences and have a great time. There is a centre (Special Education Resource Centre, [SERC]) where she goes when she needs assistance. She also expresses that, the centre is where she thinks she should go if she needs help. Sometimes she spends a night, days or weeks at the centre or in town and later returns to her home.

Living in one of the least developed areas in PNG without the availability of services for people with disabilities has made life complicated and difficult for

Angie. What comes through strongly in Angie's interview is that her everyday struggles and challenges have made her more determined to push herself and do things on her own each day. While she lives close to extended family, she manages on her own in most aspects of her life.

When the interview ended, I gave Angie a small sum of money to assist her to travel home. I also gave her a thank you gift. The gift was in the form of a mat, which she said she would use on her bed. She mentioned that at the time she was using a piece of canvas to put on her bed, which reflects her poor living conditions, so she really appreciated the gift I gave her and I appreciated the gift she gave to me in sharing her story.

4.2 Case Study Two: Essie

Background

Essie is 24 years old and is originally from April village in a province of PNG. Essie and her twin sister were born with cerebral palsy. Her twin sister died soon after the birth while Essie survived. Essie did not mention anything about her father. Essie and her mother are currently living at X with her elder brother and his family.

Essie is hemiplegic which means that one side of her body is affected. She uses the left side of her body to conduct her daily activities. She needs supports when climbing mountains or hills. Although they live with her elder brother and his family, Essie and her mother have a separate cooking place. She especially likes doing the dishes. During the interview I discovered that most of Essie's responses where very short and she had difficulty pronouncing certain words. I come back to this observation at the end of the narrative. Although she was 24, she spoke like someone much younger than her chronological age. I include my own voice in this narrative as most of her responses were single words, phrases and very short sentences.

Essie's Story

Essie seemed very pleased to be talking with me. She had brought something with her to show me.

> *…I was happy to come…This is the book, which you asked to see* [referring her medical record card]. *My mother gave birth to me on the early hours of a Monday morning.*

She spoke about what she does at home.

> *… I do the dishes and …I do my own laundry. I sweep and collect rubbish at our place. My main daily task is washing plates… I remove and empty the rubbish … This one* [her left hand]*… I will lift it* [referring to when she lifts things] *with the left hand…*

I noticed that Essie could not walk very well, but she told me with pride that she walks independently.

I walk… I walk independently, I can get on the bus… I use my leg… I walk…

She also mentioned that she has a good relationship with her family.

I move around with them… I like all of them…

She recalled an incident where their house was set on fire.

When we were at Grey, our house got on fire and I ran… Shane burnt it, Shane from Green, he was mad at Benjie [Essie's elder brother] *and he cut his hand off…*

She also spoke of her hopes and aspirations for further learning and development, perhaps even getting a job.

I want to write using a pencil and a book… teachers at the centre teach me how to write, Katy and I go there, [we] *write and then they* [referring to teachers] *tell us to play, there are different games…I want to be a teacher…*

When the interview ended, Essie mentioned that she did not want to go home so quickly.

Reflection

Although Essie has a disability, she did not appear to see herself as a disabled woman. Most of her responses were single words or phrases or very short sentences. This could be due to the presence of a cognitive disability as well. Whether this was present at birth is unknown. Although her disabilities are pronounced (intellectual and physical), she has managed to make her own support network of family and community members.

When I went to her place, I found that she had some friends. These friends include family members and close neighbours. She interacts well with them. Essie spoke very little about her relationship with family members, but what she did say showed that she has a good relationship with them. She also talked about her elder brother, which shows how close she is to him. Essie enjoyed the time she spent away from the family home, which reveals that she was happy to meet new people.

The fire story indicates the difficult living conditions of the family and the lack of effective community support services for them. Essie's health condition at birth \affected her development also indicates the unavailability of effective basic services including health services in her community.

Essie sounded fairly positive about how she managed and coped in her environment. Several times she mentioned that she has to do the dishes, revealing that this is what she does at home every day as part of her daily routine. However, she also shared her hopes and aspirations, which are to be educated and become a teacher. This could also reflect the interaction the teachers have with her when she visits the centre. At this stage, Essie needs to be taught further life skills to assist her to grow and develop as an individual.

4.3 Case Study Three: Rebecca

Background

Rebecca is 16 years old and is from a village in PNG. She was adopted into a family of eight and is counted as the fifth in her family. Her adopted father died four years ago and she now lives with her mother, grandmother and other siblings. She also has extended family who live around the village. She talks about unity, she wants to see family and others come together and unite.

Rebecca was born with cerebral palsy. When she was little, she had several different illnesses, including polio. She received many injections on both legs. The right part of her body is affected, which causes difficulty in movement. Her right leg is shorter than her left leg, which affects her mobility. She moves around slowly as she encounters difficulty with balance. However, she is young and energetic and has hopes for great things in future. At the start of the interview I asked her to choose a pseudonym and she chose the name Rebecca. She was the only participant who has chosen her own pseudonym.

Rebecca's Story

> *When I heard your message,* [it] *made me feel so happy … I was happy to come because I thought you might have some information about some form of learning for me… I thought you will be teaching me something* [new and interesting]. *I was happy to come because I thought you are going to teach me, or … take me there* [referring to the SERC]*... I thought we are going there for some activities…*
>
> *Some of my daily activities…are weeding … cooking… fetching water... I fetch water from a tank which is close by… Laundry…When I move around I feel tired, I fall… when I force myself to move around* [quickly]. *It is short* [referring to her right leg]. *Walking stick* [referring to what she uses]*… If I walk on the road and fall, my skin* [body] *gets hurt or sore and this affects me in doing some of my daily activities… illness* [also] *stops me from doing the things I want to do.*
>
> *I live with my mother and grandmother …* [and] *visit my uncles* [at times]. *I feel happy… We live together. There are times when we are happy, there*

are times when we argue. My grandmother starts the arguments. Sometimes I am wrong, sometimes I am not wrong… I don't like having arguments within the family…when I do things wrong, my grandmother gets angry at me, at times she gets very angry and that upsets me…Yesterday, my mother and I had an argument... and she hit me. [This is the usual way to discipline children in PNG] *...She then apologised to me...When she… heard that you …wanted me to come and see you… she informed me, I felt so happy. When she gets angry with me and uses acceptable words when she tries to correct me, I appreciate and accept it. But when she uses harsh words, I am not happy, it upsets me.*

…I can tell from people's faces when they move around. I can tell by women's facial expression… that they are not happy [when I am around]*...I just move pass them, when they make comments that are upsetting. I don't feel good… I tell my grandmother. My grandmother just listens to what I say and tells me to forget it. I tell my mother … and she says when they do bad* [things] *to you, you should do good to them…*

When I move around, I see others stare at me and that makes me feel that I have a disability… [I feel] *different… they stare at me and sometimes they make comments… Comments such as 'that girl walks up and down'. I feel bad… at times I feel, I shouldn't be hearing such comments I have a small sister and I feel different from her… At times when people around me look happy and talk to me in a nice way I respond to them…if they don't talk to me in a nice way, I don't respond* [referring to the name calling]*. I feel different, sometimes I accept it* [name calling] *sometimes I don't respond. Sometimes I get angry and ask them, "how do you feel when you call me such names, do you feel good?" They will just laugh…*

There is a name 'Shay' [pseudonym]*. There was a time when boys were making fun and one called me Shay. I don't know why they called me Shay, but when they called me by that name, I just responded…by saying yes…* [The name was used as a nickname with no derogatory]...

I attended Mango Primary School, I completed Grade 8. I started from Grade 3 to 8. I learnt [some] *English. I can read and write. I learnt* [the

subjects] *Using English: Create and communicate* [referring to a units taught in the Grade 8 English]*…Maths, social science, science… we did arts as well. In arts, we made stars, using sticks. We also made paper birds. I enjoyed it* [arts lesson]. *In some* [activities] *I did well. I was happy. When the teacher told us to make fish baskets* [baskets that they put fish in, as part of a practical assignment], *I failed it…it was untidy and did not look good. I felt very bad because I did not get marks for that…* [because of] *untidy work… other …* [students] *did well…*

… Some teachers came and whispered answers to students to put on the answer sheet. Some followed [those] *answers while some didn't, some cheated … I was happy to do exam, when I saw this* [that there was cheating going on] *I thought… if I pass* [the exam] *I will accept it, if I fail the exam.. I will* [still] *accept it. When the results came…only two* [students] *were selected to go to high school. The rest of us were not selected. We all stayed* [home when school started in the following year]. *I wasn't happy to stay at home, I wanted to go to school… if I did well in Grade 8* [and continued to secondary school and college] *I want to become a primary* [school] *teacher.*

… I am happy to be involved in drama…and dart game… In June [every year] *we normally go to …Peter's place to celebrate the Children's Day some of us* [referring to children] *take part while others go and observe and celebrate with everyone else. Some of us are happy, we celebrate with them, interact with them and participate with them in activities… During Children's Day, they perform action songs which is difficult for me to do.*

I do meet Jenny… I talk to her, but she has speech difficulty and cannot verbally respond to me, so she tries to communicate with me using signs…. I also meet Brenda… She is blind. When I meet her I say 'hello' to her. I usually meet her in town. She goes to town with her sister. [Brenda's sister guides her around]. *She* [Brenda] *is happy when she meets up with me. She hugs me, I like her too…*

Ms Katy told me that when there are activities, they will send word for me to go… We played volleyball. I enjoyed the game. We [people with

disabilities] *went to the Centre, Ms Katy, told me to get into the court and play…. I played a game of sitting volleyball, we sat on the grass and hit the ball.* [After that] *I watched other people* [with disabilities] *play other games… It was interesting, [to watch everyone play and enjoy themselves]. I feel happy to move around, but I like it more when we* [referring to all people] *all walk together.* [This can also be interpreted as having all people united].

I want to be teacher, I want to go …and teach in Mango Primary School [her former school]*, which has been run down…* [Act] *drama, I can sing… When we meet and have fun. Like, coming together, telling stories, being happy. That is what I like. I want to see unity. I am happy……I am happy. I am happy that God has created me. That is why I am alive... I was born with it. I was born with many different illnesses such as polio. I used to get many injections on both legs… I view myself as a person living with a disability …*

Reflection

Rebecca's congenital condition and her early childhood illness have affected her mobility and balance system. Rebecca acknowledges and accepts that she lives with a disability. She actively performs her daily chores like any other woman in the community. She is happy with her family members and feels she is part of her family, yet she is not happy when there are arguments in the family. However she feels that she is 'different' because of the perception of others and their attitudes towards her. She also feels discriminated against because of the words other people use towards her, describing how she moves around. As a young disabled woman it is not easy for Rebecca to accept these views about her.

Rebecca is happy when she meets other women and people with disabilities as it gives her a sense of connection, particularly with other friends who are disabled. She happily participates and celebrates with other people with disabilities. This is where she feels a sense of belonging and feels accepted. When she heard that I wanted to see her she thought I was going to take her to the centre to learn something. This reflects how she misses school and the experience of being a

learner. This also indicates that she still hopes to go back to school. She lives in hope that the centre will be the best place for her to go and learn new things.

Even though she experiences other people's dismissive perceptions towards her, she is comfortable and happy in herself and speaks greatly of her interests and ambition in education and learning, and the type of job she aspires to do in the future. Because the primary school she attended had poor performance, her hope is to be a teacher so that she can return to her former school to help improve it in some way. This thought shows that she is determined to improve the lives of others as well as her own.

During the interview, Rebecca revealed that she wanted to see unity. She wants to see people move around together and be united despite their differences rather than being disconnected from others. Although she revealed in the interview that she feels different, she acknowledges that she is disabled and is determined to be a teacher and return to her former school and improve it.

Rebecca is the only participant that has attended school and has received some form of formal learning. This shows how she feels about herself and how she values her contribution.

4.4 Case Study Four: Gee

Background

Gee is 26 years old and comes from Cres village in PNG. She is the fourth in a family of six. She has three brothers and two sisters and lives with her family. She was born with cerebral palsy which has affected the right part of her body, thus impairing her movement.

When I arrived and asked for her, I had to wait for her mother to call her because she was in the bush collecting greens to cook. At that moment I discovered that Gee must have had a bad morning before I arrived. I assumed she must have had an argument with a family member or a disagreement and was unhappy about something. Her mother mentioned to me that Gee was not happy about something at the house that morning. The moment Gee learnt that I was present at her place, something shifted in her: she left what she was doing, went into her room, picked up her bag and walked towards me. I could see on her face that she felt relieved and happy when she noticed my presence.

Gee's Story

> *My name is Gee* [she gives her full name]. *I am a disabled woman. Just after my mother gave birth to me, I acquired this disability. I could not walk well when I was younger… now that I am older, I am able walk* [but not too well]. *My mother gave birth to me in a hospital and later went and lived in the village…We grew up in the village and later returned to Roku* [her current location]*…one time I was unconscious…they brought me to the clinic, and that was when they pushed tubes into my nose and put drips into me. All that time I was unconscious. I was not able to move my hands and legs... One part of my body, the right side was paralysed... from the brain to the leg... I am not able to use this; I only use this to do work* [referring to the left hand and leg].
>
> *… I am a hard-working woman, I like to work, I do not just stay and do nothing... I weed around the house… I do my own laundry… I usually cook... chop fire wood…into pieces, tie it into bundles and carry the bundles of wood to the house… I do many things alone, cut grass around*

the house, rake, remove rubbish, [and] *clean up the house. … I do the dishes too... I do most things independently…*

I know I am a disabled woman because I am disabled. My brain and one part of my body are paralysed. The paralysis [condition] *got one side of my body from one side of my brain down. The right side is not functioning. The left side is ok… I am different to my sisters in the… my family knows I have a disability… When malaria hits me, I get very weak, I feel so weak and dizzy that could make me fall…*

…Some things are hard… Many times, they [referring to her immediate family] *make things difficult for me, I give up and run away sometimes. They don't treat me well. Some of their ways are not good towards me. In the family home they mistreat me… But some of their ways are good… I am worried most of the time. I am not always happy, that is how I live, sometimes I am happy, and sometimes I do not let that bother me. I am the type of woman who is not too easily affected by how they treat me, that's why I am not deterred by how they treat me. Sometimes I crack jokes to laugh and forget the maltreatment…my youngest sister Sophie usually argues with me. We had an argument last year… my family members usually mistreat me* [she whispers]*…They mistreat me but I try not to let that distress me… I just have to accept that... Sophie verbally accuses me many times. … Before the argument, we used to share things…*

…. Last year we had a very big argument and I left the house to live with Betty…Our parents don't say anything, our mother will weigh things out while our father will be biased, supporting Sophie. Even in other arguments they support others and not me…that makes it very difficult for me. When it becomes too difficult to bear, I will just sit [and not say anything]*, if not I will leave, to go and stay with Betty. When I am with Betty I am happy… my youngest sister treats me unkindly. She verbally accuses me but I dismiss her arguments and later make peace with her… I am the one who initiates peace… When I am angry, I want to fight. I am a woman who retaliates when provoked but I also …have that peace in me, when I am angry, I usually sit and think… that is when I find peace…*

I am a female youth of St. Philomena group…. On St Philomena's feast days, we have celebrations... We normally go and pray at Irene's place… I am happy about it…that's the only group I am in…the community, I don't have a good relationship with other people…

I am still learning to make bilums. I walk around with… Betty,… so that I can learn from her … To find peace I usually walk to Betty's place…many times I leave the family home to stay with Betty… that is when I am most happy. I stay with her for as long as I want before returning… when I leave home and go out, ooooh, I forget about everything that happens in the family home… when I return…the same thing happens. When I attend prayer meetings with friends, I find that prayer helps me… when I leave the house, I feel happy…

Reflection

At the start of the interview Gee introduced herself, acknowledged that she is disabled and spoke about how she acquired her disability. She was born with her disability and was very sick in her childhood. This has affected her right part of body as well as her mobility. As a young woman from PNG, her daily life activities are just like any other woman.

She is young and energetic and her story revealed how independent and hardworking she is. She conducts many daily chores independently and she seems to have a plan of what she wants to do each day. However, she also has malaria and this can make her feel exhausted.

In the interview, perhaps because of difficulties earlier that morning Gee spoke most about the mistreatment from her family in the family home. Her family's words towards her are not acceptable and are also upsetting. During arguments in the family home, she does not seem to be supported even when she needed someone to speak up for her. However, she is accustomed to the treatment she receives and has become resilient to it. When she feels she cannot help herself, she leaves the house and lives with Betty (a close friend who lives nearby), where she is most happy, at peace and feels sense of belonging. Although she has gone

through a lot in her own family home with her immediate family, she seems to be independent, strong and resilient.

During the interview she expressed that she also finds peace when she is with her youth group for prayer meetings and other activities. The youth group is a welcoming space for her to socialise with others. The good connection she has with her female peers in the youth group has helped her to develop friendships with other females in the community.

Gee is from one of the least developed provinces of PNG where the basic services that are available are ineffective and inefficient. Her story reveals many factors affect her life as a disabled woman. These factors include poor services available in her area; the poor economic status of her province; the poor living standard of the residents of her province, and unavailability of support services in her community and her province.

Gee mentioned that she went to school and did Grades 2 and Grade 3. These are classes taken at ages 8-9. In the classroom, she was not able to write and received little assistance from the teachers. Now that she has grown older, she is not able to read and write well, feels that she is not capable of learning and does not want to go back to school. Her low level of literacy could reflect the lack of services available to assist children with disabilities into mainstream classrooms, the type of educational services available, and the lack of resource personnel to assist her and other children with disabilities. Her lack of confidence in attending school and receiving an education also reflects the type of support she needed, but which was not available.

Although she has encountered difficulties and challenges in the way others perceive her and treatment she receives from her family, in many ways, Gee lives the life of a typical PNG woman. She is able to push herself to do as many things as she can live her daily life, dependent on her health. Her life as a disabled woman is affected by how she is treated by family, the type of support for women with disabilities in her area, and the physical and organisational structures that make up her society.

4.5 Case Study Five: Amber

Background

Amber is 35 years old from PNG. She was born with her right arm shorter than the left. Her right arm ended at the elbow. She uses her left arm to carry out daily house hold chores while she supports herself with the right arm. Amber has been involved in Paralympic sports on various occasions in PNG and has also travelled overseas to participate in Paralympic games. She has great memories of her experiences abroad. When she got married, she stopped participating in the Paralympic games, but she hopes to return to Paralympic sports in the near future.

Amber's Story

> *...I live as a disabled woman… I accept it...*
>
> *I conduct daily household chores, wash plates* [do the dishes], *cook food, cut firewood. … I do everything by myself… I hold the axe in one hand* [left hand], *and lift it to break firewood, scrape coconuts. I do everything using one hand only. This hand supports the other while I scrape coconuts to make coconut milk* [from coconut flesh]*…It is difficult… I have difficulties when I chop firewood, I* [usually] *ask others to… help me … I ask young boys* [relatives to help].
>
> *They call me … short hand* [referring to one of her hand being shorter than the other]. *I hear that but I don't bother telling them* [to stop]. *I do not get upset. I just accept it. That's how they call me. They call me names when they see me, at times they make fun of me… I don't let that bother me, just accept it. I feel that, it is not ok.* [But] *I do not tell anyone* [about how I feel]. *I just listen… When I want to rebuke them, they say, "you don't have a full arm, you hand is short, that's why we call you that…*
>
> *I don't have the chance to meet them…* [Other women with disabilities] *I don't move around, I stay at the house… Because we live far from each other…*
>
> *I did not go to school…My mother gives me instructions on (what to do) and I follow* [her instructions] … [if she had gone to school, she would

have wanted to be] *...A teacher… Go to school, get educated, become a teacher… High school* [teacher]*… I admire the knowledge they have…*

I went to Australia, I went to town B and Town C. It was nice. Playing [Being involved in Paralympic games] *is the only good thing in my life. I ran* [in a race] *against people from other countries. I was in Australia for two weeks, I was sponsored to participate… I must go back and play…I don't feel too happy, I want to be able to go back and play… I told my husband, after delivering this baby, I will be looking into going back into Paralympic sports. He is happy with it.* [I will] *go for an operation* [tubal ligation] *and wait …to get me back into the games…Everyone* [in my family] *agreed that after giving birth to this baby, I should go for tubal ligation and continue what I have started* [in para sports] *and I agreed……I have a good relationship with my family members. My family accepts me…… My in-laws come and help… care for the baby, help me to cook, sometimes they help to look for firewood and coconuts… I sell things at the market…betelnuts and mustard...*

While Amber said that her husband supported her to return to the Paralympics, she also included the following remarks.

My husband… stops me. He thinks that, I might not return to him after the games. I was supposed to go and play when the games were hosted at Town C last year…My husband did not want me to go. He said heard stories that if I go, I may not return… I may be selected to continue participating in Paralympic sports. Because of such stories, he did not allow me to go…. That was the reason he stopped me… To be honest, when he stopped me, I was terribly sad and upset… I said, it is ok [for now], *but next time, if you say No, I will not stay. I will go* [for Paralympic sports]*…and come back... My greatest interest is to go back to Paralympic sport…*

Reflection

Amber acknowledges that she is a disabled woman and she accepts it. She conducts her daily activities like any other woman in her community who has responsibilities as a mother and a wife. She does most of her daily chores

independently and seeks help only when necessary. Like the other women with disabilities, she lives the life of a typical PNG mother and house wife, where her responsibilities are centred on her family and home. This also makes it difficult for her to connect with other women with disabilities as she used to do when she was living a single life. She feels she has a responsibility as a mother and wife and has to submit to her husband. Her family commitment also limit her chances to socialise and interact with others.

However, she has a good relationship with her immediate family and she gets most of her support from them. She also has a good relationship with her husband's family and she and her husband live with them in the same village.

Her challenges are having to deal with the stigma and discrimination other community members have towards her, especially in the words used to describe her disability. There is no support available to help her challenge this verbal abuse. Her day to day life is accepting other people's perceptions, views, and assumptions of her. The 'name calling' has been part of her whole life and this has become something that she accepts. She feels discriminated but she is resilient. Her greatest motivation is in Paralympic sports and it seems that it is in this environment that she feels fully accepted. However, it isn't clear whether she will be able to realise her dream. While she said her husband was supportive, she also revealed that her husband was apprehensive about the possibility of her not returning to the family.

She shares that she did not have the chance to go to school when she was little. At this point in the interview she became emotional. Most of her learning of house hold chores was by observing and following instructions from her mother. Here, local beliefs that disabled children are not capable of learning and acquiring new skills affected her life as a disabled child.

CHAPTER FIVE

FINDING AND DISCUSSING KEY THEMES

5.1 Introduction

This study explored the views and experiences of daily life for women living with visible, physical disabilities in a rural setting in PNG. While research on the situation of women with disabilities is well documented internationally in developed nations, research in this field is rare in developing countries such as PNG. The narratives of the participants indicate that both the socio-cultural practices and the physical environment substantially influenced their level of involvement in their communities and the type of treatment they receive. These influences are both positive and negative. However, they indicate that gender discrimination and social injustice still occur within the status of PNG as a developing nation.

The goal of this research thesis was to *give voice to women with disabilities* in PNG. By raising awareness of their concerns, struggles and daily realities, I hope that the study will contribute to the small body of literature on disabled women in the Pacific region and that the study will have significant implications for the type of existing policies and practices that concern *women* as well as *people with disabilities* in PNG.

This chapter seeks to explore key themes that emerged from the narratives presented in Chapter 4. Salient superordinate themes (Walsh-Gallagher, Sinclair, & Mc Conkey, 2012) emerging are presented and explained. Each theme area is considered in relation to the individual's views and experiences. Although themes are categorised, they are also interconnected. Further, through the IPA framework, I include aspects of the dynamics around their views and lived experiences, specifically, what I as a non-disabled PNG woman see as the factors that surround their experiences as *women who are disabled*. The table below shows four superordinate themes (major domains) that emerged from the women's narratives (as shown in Chapter 4).

Table 2: Superordinate themes (major domains)

Superordinate Themes
Perceptions of self, related to disability
Positive Perceptions/Affirmation
Marginalisation
Violence

The table below links the superordinate themes to constituent themes that emerged from the narratives.

Table 3: Superordinate themes (major domains) and constituent themes

The *views and experiences* of daily life for women living with visible, physical disabilities.

Superordinate theme	**Constituent theme**	**Key words**
Perceptions of self, related to their disability	Self-identity Negative self-perception Responding to lack of acceptance	Identity Negative- perceptions
Positive Perceptions/ Affirmation	Affirmation at home Participants find acceptance Affirmation in community Affirmation about being disabled Hopes and aspirations Resilience	Affirmation Acceptance
Marginalisation	Stigma and Discrimination Lack of opportunity	Discriminated against Exclusion

Violence	Abuse	Verbal
		Physical
		Emotional

5.2 Discussion of themes

The first superordinate domain: **perceptions of self, related to disability;** was centred on the participants' perceived self-perceptions and the perceived reactions of others. This was dominated by the focus on the woman's disability. The second, celebrated the **affirmations** of each woman as an individual and expressed the normality of their experiences despite their disability. This theme also reveals that the women perceived themselves as *women* and as *individuals* in their families and communities. The third, **marginalisation**, is centred on their experiences as *disabled women.* These experiences are strongly influenced by the other people's perceptions, reactions, and attitudes towards the disability and the beliefs towards disability/disabled people. The experience of marginalisation was focused on stigma and discrimination which emphasised feelings of exclusion and isolation for the women. The fourth: **violence**; is centred on other people's actions and reactions towards the participants. These actions are abusive, emphasising the women's vulnerability, resulting in the women feeling helpless, needing support, unsafe, and are at risk of exploitation.

5.2.1 Superordinate the one: Perceptions of self, related to their disability

CT 1: Self-identity

Four of the participants identified themselves as *women living with disability* and indicated that they were more or less comfortable being seen this way.

> *God…made me disabled…* (Angie)
>
> *I view myself, as a person living with a disability …* (Rebecca)
>
> *…My name is Gee. I am a disabled woman…* (Gee)
>
> *I live as a disabled woman… I accept it...* (Amber)

Essie however did not see herself as a woman with a disability. This could be due to her cognitive disability, as she seemed a lot younger in her outlook than the others.

CT 2: Negative self-perceptions

While participants accepted *disabled* as a description of themselves, they were not always happy about how they were viewed by others in relation to the term.

> *... I see others stare at me and make me feel I have a disability... I feel different…* (Rebecca)
>
> *Able-bodied people do not accept me…* (Angie)

Being seen as different could result in feelings of discomfort.

> *Having a woman with disability like me brings shame… they do not want me to live with them... I felt so bad because they are not the same as me, I am different from them…* (Angie)
>
> *I am different to my sisters ...* (Gee)

Putting up with these feelings and accepting that their difference caused comments of discomfort was a strategy used by the women to cope.

> *I do not bother telling them to stop…I feel that, it is not ok.* [But] *I do not tell anyone* [about how I feel]. *I just listen…* (Amber)

The effects of being seen as *other/disabled/different* in relation to non-disabled people could affect how the women are treated at home.

> *In the family home, they mistreat me…* (Gee)
>
> *My brother in-law built my house separately from his family because his wife does not accept me…* (Angie)

Support from other family members was not always there.

> *Last year, we* [Sophie and I] *had a very big argument and I left the house to live with Betty. Our parents don't say anything, our mother will weigh things out while our father will be biased, supporting Sophie…* (Gee)

Ill-treatment for looking different could also be found in the local community.

They call me S…they say I am a snail that crawls… (Angie)

Sometimes they make comments… such as: that girl walks up and down… (Rebecca)

CT 3: Responding to lack of acceptance

Sometimes the women were able to answer the taunts they received.

Sometimes I get angry and ask them, "how do you feel when you call me such names, do you feel good?" They will just laugh… (Rebecca)

… When I want to rebuke them, they say, "you don't have a full arm, you hand is short, that's why we call you that" … (Amber)

But it wasn't easy knowing what the response was likely to be. Remaining silent was also a way to get through unpleasant incidents.

When it becomes too difficult to bear, I will just sit [and not say anything] (Gee)

The women were often left emotionally distressed when such incidents happened (which could sometimes trigger a dangerous mental state).

*This makes me feel so sad at heart and makes me think of committing suicide but I keep it all to myself and move around with a heavy heart... (*Angie)

Summary

This theme area addresses how the participants viewed themselves at the time of the interview. The narratives revealed that the participants identified themselves as disabled and they had self-perceptions that were mostly negative, and which seemed vulnerable due to high levels of self-doubts and how they responded to lack of acceptance from others. How participants feel about themselves is a way of establishing a relationship with their being as individuals, a way of making meaning of the significant moments in their lives where they felt they were disabled women. It also helps them to identify the times they felt that their disability has given them a different meaning in life because of the complications and situations that they experience as a result of their disability.

5.2.2 Superordinate theme two: Positive Perceptions: Affirmation

CT 1: Affirmation at home

As the participants' narratives reveal (Chapter 4), many talked about what they do at home. All spoke positively about completing daily activities and their competence in achieving the set tasks.

> *I do my own cooking; I scrape the coconut* [dried] *and* [extract coconut] *milk* [from its flesh] *and prepare greens … [independently]… I do my own laundry…* [I] *chop fire wood… I clean around the house... I conduct these* [daily chores/activities, all] *by myself…* (Angie)
>
> *I walk independently… I do the dishes and …I do my own laundry…* (Essie)
>
> *... I fetch water from a tank, which is close by…* (Rebecca)
>
> *…I hold the axe in one hand [left hand], and lift it to break firewood, scrape coconuts…* (Amber)

All participants contributed to the running of the house and they highlighted that these tasks were achieved independently of support from others. All took pride in these achievements and the contribution they made to their daily existence.

> *...I am a hard working woman…I do most things independently* (Gee)
> *… I do these things to sustain my living…* (Angie)

However at times the lack of support from others for the more difficult tasks was felt.

> *... I do everything by myself…It is difficult* (Amber)

CT 2: Participants find acceptance

In general, participants have found acceptance in certain groups in the community. While Angie spoke of difficulties related to living with her family, others talked about being accepted by family members without reservation.

> *I move around with them* [family]*... I like all of them…* (Essie)
> *I live with my mother and grandmother…I feel happy…we live together…*

(Rebecca)

I have a good relationship with my family members. My family accepts me… My in-laws come and help… (Amber)

When living with family became tense, Gee was able to go to stay with a (non-disabled) friend who live close by. This relationship, with a person Gee considered as *a family member*, was very affirming for her.

To find peace I usually walk to Betty's place … that is when I am most happy. I stay with her for as long as I want before returning… (Gee)

Participants are most happy when they leave the home environment because that is when they feel happy and are not bothered about what happens at home.

When I leave home and go out, ooooh, I forget about everything that happens in the family home… (Gee)

When I leave home, come out and meet other people… I feel happy. Like sitting with you now and talking, I am happy and I appreciate this because it helps gives me space to think positively… (Angie)

CT 3: Affirmation in community

All the women participated in a number of positive and fulfilling activities in their local communities. For example, selling products at the market; such an activity allowed the women to maintain at least some independence from family, as these statements reveal.

I sell things at the market…betelnuts and mustard (Amber)

I make bilums [string bags] (Angie)

For Essie, affirming experiences included being able to move freely within the community. She took great pride in this achievement in particular.

I can get on the bus … (Essie)

Other highly valued activities for the women included attending church.

I am a female youth of St Philomena group…that is the only group I am in the community… (Gee)

Rebecca was the only participant who had the opportunity to complete primary school education. She spoke positively about this opportunity. Her comment reflects the love, care, and support her family provided to enable her to complete her primary school education.

I attended Mango Primary School; I completed Grade 8… (Rebecca)

CT4: Affirmation about being disabled

While Amber never attended school, she had the opportunity to participate in the PNG Games. Later on she participated in the Paralympic games in Australia. She spoke of this experience with great positivity.

I went to Australia; I went to town B and Town C. It was nice. Playing [Being involved in Paralympic games] *is the only good thing in my life. I ran* [in a race] *against people from other countries* (Amber)

The only other participant to specifically mention her disability in any way might be read as positive was Angie who said.

Other disabled people [women with disabilities], *communicate well with me…* (Angie)

CT 5: Hopes and aspirations

All the participants were self-motivated and were determined to work hard to continue to sustain their living.

… I am a hard-working woman, I like to work, I do not just stay and do nothing... (Gee)

Further, participants spoke about their hopes and aspirations for the future. All wanted to keep learning. Three wanted to be teachers. This could reflect the impact the teachers have had in their lives through the informal sessions that they had with these professionals.

I want to be a teacher… (Essie)

> *I want to become a primary [school] teacher* (Rebecca)
>
> *Go to school, get educated, become a teacher… High school (teacher)… I admire the knowledge they have…* (Amber)

Gee spoke about learning to make bilums.

> *I am still learning to make bilums. I walk around with… Betty… so that I can learn from her…* (Gee)

These hopes and aspirations reflect the impact that teachers and special friends had on their lives. Although, most participants did not receive formal education, they spoke confidently about becoming teachers, what they admired about teachers and what they would do if they became teachers. Gee, however is interested in doing something informal such as making bilums. Angie is confident in making bilums and is able to sell at the market.

CT 6: Resilience

In order for them to achieve things independently, the participants have had to adapt to their circumstances. Here they have shown considerable strength of purpose in overcoming obstacles and they have developed resilience when they encountered situations beyond their control.

> *I do not let that bother me. I am the type of woman who is not too easily affected by how they treat me, that is why I am not deterred by how they treat me* (Gee) [meaning she has grown resilient to how people treat her – it could also mean she is accustomed to this treatment and has found means to cope with this situation].

Summary

This theme explored lived experiences that are positive and affirming. The women are able to reflect on those significant moments, making sense of those experiences as positive. This affirmation was reflected in how they communicated their experiences. The narratives suggest that despite the challenging and difficult situations these women face, they are capable, competent, independent, and resilient just like other women in their communities. They live ordinary lives and

face the same dilemmas as every other women. They carry out daily chores to sustain themselves and their families and have hopes and aspirations about possible future employment.

5.2.3 Superordinate theme three: Marginalisation

CT 1: Stigma and discrimination

All participants experienced marginalisation due to stigma and discrimination. Angie experienced dual discrimination. She has been discriminated against because of her status as a single woman, living in the same house, with her cousin, and the cousin's husband and family. She is shamed as her lack of mobility is one of the reasons that has caused the family to tell her to remain in the house.

> *My brother in-law built my house separately from his family because his wife does not accept me.* [There is also a gender issue in this comment, also, the family do not want Angie to leave her house]. *They want me to remain in the house* (Angie). Perhaps, shame, about her mobility is one of the reasons.

She also experienced exclusion around eating and food.

> *Sometimes they cook very late at night and eat, in the morning; they pretend there is no food* (Angie)

The experience of exclusion that Angie encounters evolved from a number of other issues that are interconnected: firstly, the beliefs and attitudes towards disability and people with disabilities; secondly, food scarcity and poor standard of living for the family, thirdly, lack of moral support provided by the family are also involved. These factors mean Angie is viewed as a burden to the family she lives with. The above scenario is a situation that is not uncommon in PNG communities where life is difficult in terms of scarcity of food and other necessities.

All participants also experienced instances of stigma and discrimination in the community.

> *…My cousin …wanted me to go and baby-sit her child while she goes to work…* [But] *her father and mother said I would bring shame to*

her …When people say this about me, I feel that it is degrading and shameful…they do not want me to be around them… (Angie)

I can tell from people's faces... I can tell by women's facial expression… that they are not happy [when I am around]… (Rebecca)

These difficulties caused the women to doubt their own self-worth:

Maybe I should …go live by myself… I should go [away and] *stay by myself because abled bodied people do not accept me, they do not want me to live with them here …* (Angie)

Here, Angie experiences discrimination because of people's impressions of her and attitudes towards her. She feels unaccepted and unacceptable because of the derogatory comments that have been made about her. Such comments reflect how strong beliefs and perceptions around disability can be. Again, here is a clear indication of how socio-cultural practices strongly influence how people perceive disability and disabled people can be seen. What is imposed upon Angie is more demeaning than a man in her community with a similar disability would receive because gender plays are significant role in how women are treated in their communities.

CT 2: Lack of opportunity

The women's narratives reveal that they experienced a high level of marginalisation, segregation and exclusion from various opportunities. Because of lack of finances and other resources, the women do not have the opportunity to participate in programmes that relate to their disability. For example, Angie does not have her biological family to support her participation in any activity that concerns people with disabilities. This has meant that she remains disadvantaged, and lacked the resources that she needs:

They [people with disabilities] *want to know if there is any form of training* [education] *or any gathering for us, people with disabilities or if there are any games* [sporting activities/events] *for persons with disabilities... I will tell them, I have not heard anything…as for me, I do not have money* [funds] *to support me* [participate in such activities] *…I often struggle a lot because I do not have a family…* (Angie)

In particular, Amber's opportunity to participate in the PNG Games was also denied because her husband stopped her. In this case, traditional ideologies also play a role in what is happening for her. She thinks that as a wife, she is required to be submissive to her husband.

> *My husband… stops me. He thinks that, I might not return to him after the games. I was supposed to go and play when the games were hosted at Town C last year…My husband did not want me to go. He said, he heard stories that if I go, I may not return…* (Amber)

Participants also lack other opportunities such as education and health care.

> *I did not go to school…My mother gives me instructions on* [what to do] *and I follow* [her instructions] ... (Amber)

Summary

This theme area shows that women are marginalised at home and in the community. Although theme two shows that women's lives are affirmed, this theme reveals that they experience stigma and discrimination and are excluded, segregated, disempowered and disrespected. They are disadvantaged and are denied access to equal participation, equal opportunities and basic human rights. As a result, they have an extremely low status and continue to live as a minority group within mainstream society, with no recognition and no voice. They continue to remain silent. This theme area demonstrates the need to raise awareness on the concerns of disabled women and to review existing policies that concern this group. It also illustrates the need to empower women to speak out and address their concerns.

5.2.4 Superordinate theme four: Violence

As the narratives reveal, community members take advantage of them because of their disability, their gender, and the lack of support that is available for them and their specific needs. Angie's story shows that she was abused as a disabled woman when she was receiving support. The issue is not just lack of support, it is also being taken advantage of when support is given.

CT 1: Abuse

Gee experienced discomfort in the home:

> *My youngest sister treats me unkindly…* (Gee)

The participants experienced verbal abuse. Name calling sounded very negative for the participants. Non-disabled people took no notice of how the participants felt because the participants had no support and were never in a position to speak up for themselves:

> *They call me…short hand… They call me names when they see me, at times they make fun of me…* (Amber)...
> *When they are angry with me they say the way I move around is like how ducks and chickens move …* [and] *they say I am not worthy…*(Angie)

Gee experienced abuse by family members:

> *Sophie verbally accuses me many times…* (Gee)

Angie was abused by non –family members. *Being disabled* could also result in physical abuse both inside the house and in the community:

> *…. He got my crutches and was about to violently hit me on the head but I blocked it with my hand… The nut on the crutch left a bruise which became sore… He broke a bone on my leg…* [He] *came straight to me at the back and hit me ... he really forced himself to my house…he kicked the door…* (Angie)

When this kind of violence takes place, the women do not seem to have support. Strong emotions felt at this time means that they are unable to speak about what is happening to them:

> *This makes me feel so sad at heart and makes me think of committing suicide, but I keep it all to myself and move around with a heavy heart...* (Angie)

While Angie was an in-patient receiving treatment for her injury, she was sexually abused:

> *… When I was at the Centre with the broken bone, this person* [Someone responsible with helping people with disabilities do exercise] *pushed the*

door of the room where I was sleeping and said he wanted to ejaculate, (Jones)*… it was in the night, everyone was asleep, he asked but I declined, no one knew what he did. He came back the second time and asked but I said No…* (Angie)

Often, the environment is not safe for the women. However, they can receive help from other community members at times. Yet this support is not enough for the women to feel safe in communities:

…When I screamed [for help], [some] *villagers came and he ran away. That is why I don't feel safe moving around by myself…* (Angie)

Summary

This theme explored the women's experiences in terms of the physical and non-physical types of violence that they experience. These include threat, neglect and intimidation and mostly negative interactions with family and community members. At times community support is there but is not enough. Often, women struggle with these issues on their own. This theme reflects concern for safety and protection for women with disabilities and demonstrates the need to do more work on policies that promote safety and wellbeing for women with disabilities.

5.3 Discussion

All theme areas reveal a complex picture of the lives of disabled PNG women. It can be concluded that participants could identify themselves as disabled. However, this identification was largely based on a negative self-appraisal due to lack of acceptance from others. Their sense of self was strongly influenced by other people's views and assumptions about disability and people who are disabled. Their narratives indicate that socio-cultural practices in PNG society have a significant influence on the widely held beliefs, perceptions, and assumptions towards disability and disabled people (Byford & Veenstra, 2004; Kuzma et al., 2016; Mapsea, 2006). These are evident in the day to day experiences of the participants of this study. These perceptions continue to disadvantage them in their communities. In response to a lack of acceptance in the wider community, participants seem to have accepted that they are different. Being different and being seen as different could develop a new identity for these women (Hans &

Patri, 2003), which can be negative. How being seen as different might become an asset rather than a liability for disabled women in PNG is a question for further research.

From the participants' narratives, it can also be seen that participants have positive perceptions about themselves, both as women and as disabled women. They are self-motivated as much as possible; they live independent lives and are able to sustain themselves. In addition, two participants communicated messages of affirmation as disabled women. All the participants spoke positively about completing daily activities and their competence in achieving their set tasks. The finding that participants were independent in performing the daily activities at home engendered feelings of confidence and self-appreciation of completing daily tasks with independence and competence. In PNG, women are viewed as key producers in their families, thus these examples, and the narratives are not uncommon in PNG where life for women in rural remote communities is difficult and challenging (Hinton & Earnest, 2009; Mikhailovich, Pamphilon, Chambers, Simeon, & Zapata, 2016). This finding is supported by existing literature on women with disabilities which indicates that regardless of their limitations, women with disabilities adopt positive measures in their own ways and make significant contributions in their communities (Boylan, 1991; Nosek, Robinson-Whelen, Hughes, & Mackie, n.d.; Spratt, 2013). However, their contributions are not acknowledged or recognised (Spratt, 2013).

The narratives gathered are empowering despite the difficult challenges the women encounter in their communities. The stories reveal the values of courage, strength and determination. Their situations compared to able-bodied women are severe and complicated, yet their stories revealed hope, determination and resilience. Both able and disabled women develop resilience and self-reliance This helps them provide for them and their families (Hinton & Earnest, 2009, 2010). While this is the case for all women, women with disabilities can find it hard to adhere to the day-to-day lifestyle and situations because of the already difficult, challenging and complex situations in their communities.

From this study, it can be argued that women with disabilities are marginalised in different areas of their lives. The experience of being marginalised is evident in

the participants' narratives because they are viewed as *other/, disabled/*, and/, - or *different* to non-disabled people, as the word *different* seemed to have appeared in all the stories except, Essie's. Also, the way they are treated has a negative impact on their daily experiences. People's perceptions, actions and attitude towards them have affected them in many ways. Several other studies also confirm that women with disabilities are marginalised in society (Barranti & Yuen, 2008; Sands, 2005; Spratt, 2013). Existing literature also suggests that women with disabilities in developing countries are one of the most marginalised groups (Boylan, 1991; RI/GWWD, n.d.; United Nations Enable, n.d.)

It is clearly evident in the narratives that the participants experience stigma and discrimination. Throughout the interviews, participants spoke about the type of treatment they received from family and members of the wider community which made them feel different. The feeling of being stigmatised and discriminated against, generates low self-esteem, doubt, and a lack of acceptance. This has caused the participants to not recognise their value as *women*. Literature on women with disabilities confirms these accounts. Indeed, when further compounded with factors such as socio-cultural beliefs and practices, women with disabilities experience multiple forms of discrimination (Stubbs & Tawake, 2009; United Nations Enable, n.d.)

Socio-cultural practices have a great impact on how able-bodied people perceive, treat, and react towards people with disabilities (Kuzma et al., 2016; Mapsea, 2006). As it is evident in Angie's narrative in particular, her disability brings shame to the people around her. As a result, people in her family want her to stay in the house and not leave. Angie was the participant who reported experiencing the most discrimination and stigma around disability. Her story was full of experiences which were challenging and very difficult. This could be because she has no one in her biological family living with her, or she did not feel comfortable enough to share the experiences that had affected her deeply with the family she is with. She felt comfortable sharing her story with me. However, all the women reported experiencing verbal humiliation through name-calling and labels describing how they moved around. Because they are women from a patriarchal society, the level of stigma and discrimination is very high.

The women's narratives reveal that they are socially excluded in various aspects of life. It is clear that "social exclusion is a complex concept that encompasses a variety of interconnected process and problems" (Hutchison, Abrams, & Chritian, 2007, p. 30). Yet, all the participants experience exclusion in slightly different ways. Exclusion challenges participants', this finding is supported by existing literature on women with disabilities, (Spratt, 2013; Stubbs & Tawake, 2009) a "review of research on the consequence of being excluded from desired social relationships or groups as well as the psychological process through which this occurs" (Hutchison et al., 2007, p. 30). Another study on the lives of disabled women in Nepal (a developing nation), found that four women felt excluded in their own homes (Dhungana, 2006). The women were told to remain in one part of the house without talking when family and neighbours come to their house. This finding is similar to Angie's case where she was told to remain at the house and not leave. Four of Dhungana's (2006) participants felt excluded by their very families. Dhungana's (2006) participants live with biological families and are treated this way, while Angie does not have a biological family. Comparing the previous study, with the current study, it can be argued that, whether a disabled woman lives with her biological family or not, the treatment she gets can be quite common. Interestingly, the participant who did not speak much of exclusion was Essie. As mentioned earlier, this could be due to her cognitive disability.

While the participants spoke about not having friends or not having relationships with family members in their communities, they also experienced social exclusion in different aspects of life. This contributed to the participants of this research have a lack of perceived self–worth (as discussed in Section 5.2). This lack affects how they view themselves. Although each of them acknowledged that they have a disability, their views about themselves are strongly influenced by other people's views towards them.

Education was one of the primary places where the participants experienced exclusion. They did not have the same chance to go to school and be educated as their non-disabled peers. Previous research has shown that there are a variety of reasons for this, including, limited opportunities available for disabled children in their communities to get into school; insufficient training for teachers to support children with disabilities; lack of appropriate facilities and support available as

revealed in the narratives and the reflections. In cases where the participants had the opportunity to go to school, learning was informal, as revealed in Essie's and Gee's narratives. This could be due to the severity of their disability. Where one had the opportunity to attend a formal school, as in Rebecca's case, the support she needed was not provided to enable her to continue secondary education and to college. This finding is supported by existing literature on people with disabilities. A study conducted by Mapsea (2006) in PNG regarding teachers' views on providing for children with special needs in inclusive classrooms. In his study, Mapsea (2006) found that parents keep disabled children at home because they perceive them as inferior; and feel that it is a waste of time putting them in school.

These narratives suggest that women with disabilities in PNG are vulnerable to different forms of abuse and the actions they can take to help themselves are limited. Angie has shared experiences of how she was physically abused by a young man in the community. This experience is probably widespread and can take a variety of forms including, verbal, physical, sexual and emotional abuse. These findings are supported by existing literature on women with disabilities (PIFS, 2013; RI/GWWD, n.d.; Stubbs & Tawake, 2009; WWIRGEEW, n.d.). A national study that was conducted on women with physical disabilities found that "abuse is a very serious problem for women with physical disabilities [and] [t]hey have even fewer options for escaping or resolving abuse than women in general" (Nosek, Howland, et al., 2001, p. 6). Other studies which also confirm this finding are (Nosek et al., n.d.; Pinto, 2016; United Nations, 2006). From this study, it can be seen that women with disabilities experience violence and abuse due to the intersectional nature of discrimination related to gender and disability. As women, they experience discrimination; and as women with disability there is another level of discrimination added to them. This finding clearly indicates that safety will remain a concern for women with disabilities in PNG and that there is a great need for awareness raising at the community level to address the concerns these narratives raise. However, it is also noted that poor economic support, lack of support from family, and socio-cultural practices also add another level of discrimination which marginalise these women. This finding too is similar to a study conducted by (Stubbs & Tawake, 2009) on the issues and challenges faced by women with disabilities in the Pacific.

5.4 Summary of the Chapter

In this chapter four key experiential themes are presented. Each provides insights into the lived experiences of the women with disabilities in a wider sense that link to other research findings about the life-experiences of women with disabilities. These theme areas suggest that the focus on the interconnected elements in the themes is a unique way of authenticating the lived experiences and concerns of women with disabilities as a vulnerable and at times voiceless population group. The final chapter that follows, concludes this research by discussing the key points that were revealed in the findings of this study.

CHAPTER SIX

CONCLUSION

Identity

> *My disability is the fundamental factor in the being that is "me". I do not want to deny this by calling myself "a person with special needs" or any other euphemism, nor do I want to deny the collective identity we have achieved ourselves. Therefore I am a disabled person and proud of it.* (Mason, 1992)

6.1 Introduction

This chapter concludes this thesis. The first section begins with my interpretation of the above quote. I then make sense of the phenomenon—the views and experiences of daily life for women living with disabilities—by finally bringing together the main findings and their significance. The second section presents the benefits and limitations of using IPA in this study. Following, is a section on recommendations, and another, on implications for future research. I then include a section with my reflection and a final statement brings this chapter to a close.

6.2 Summary of the main findings and their significance

As Mason (1992) suggests, when identifying who they are in life, people with disabilities invariably must contend with non –disabled people's thinking of them and their interpretation of the word, *disabled*. In particular, women with disabilities "are often perceived as weak and dependent" (Morris, 1993, as cited in McDonald, Keys, & Balcazar, 2007, p. 147), a position that can impact on how they feel about themselves, their identity, and their value in their community. The way disabled women feel about themselves is strongly determined by other people's attitudes, actions and behaviour towards them (as discussed in the previous chapters). While as a non-disabled woman, I do not have the experience of living with a disability, there are experiences that are common for all women in my society.

Throughout the whole process of this research, I attempted, as a non-disabled woman, to explore the meanings of the lived experiences of daily life for the participants that emerged from the narratives about their individual experiences. I

wanted to provide a theoretical platform for further investigation into their daily life experiences. In accordance to the principles and guidelines of the IPA approach, the thesis was able to provide me authentic information and insights into the views and lived experiences of women with disabilities in rural communities in PNG, a developing nation in the Pacific (Aisi, 2014). I recommend IPA as an accessible approach (Yoo, 2014) to anyone exploring the lived experiences of marginalised groups, and to offer an interpretation of this perspective to researchers in the field of disability (Smith et al., 2009). I found that women with disabilities in rural communities in PNG are bound up in a complexity of experiences. Socio-cultural beliefs and practices strongly influence the attitudes that able-bodied people have towards them (Mapsea, 2006). Although, women's values are gradually becoming more recognised and respected in PNG society today, the perception that society holds towards women as subordinates or inferior to men still prevails (McNae & Vali, 2015; Vali, 2010; Yawi, 2012). This is because patriarchal attitudes and perceptions about gender are widespread in the country and thus women in PNG still experience gender inequality and discrimination (Hinton & Earnest, 2009; Vali, 2010; Yawi, 2012). The socio-cultural context also strongly influences the quality of life for women with disabilities. It also affects how these women experience their physical disability, yet each of the women's disability/ies has different consequences in different day- to-day functions.

In the previous chapters of this thesis, I briefly examined the term *ableism* (see section 2.3). Here, I offer my insights on the effects ableism in regards to myself as a non-disabled woman researching the views and lived experiences of disabled women. Wolbring (2008) claims that "[e]very ism has two components [;] [s]omething we value and something we do not. The subjects of isms can be negative or positive" (p. 252). In this thesis journey, I discovered that ableism affected my thinking around the work I did in this study, as well as the thinking of the participants of this research. In this study, I viewed the participants according to their abilities, not within the context of 'disabled people' but from a broader perspective (Wolbring, 2008). The narratives (see Chapter Four) reveal that the participants are hardworking, competent, creative, independent in many ways, have hopes and aspirations, and have supported themselves in their day-to-day

activities. The negative views that people have about them supresses and disadvantages them. However, due to the difficult situations that they are faced with as women from rural communities of a developing nation, they work hard to sustain themselves. However, did I, as a non-disabled woman, fully capture their experiences as disabled women? That is, would, a disabled woman have been told different things, seen different outcomes in the data? It is hard for me to say and an idea that should be taken further.

6.3 Benefits and limitations of using IPA in this study

Using IPA in a qualitative study can be both challenging and rewarding. One of the particular difficulties for this study was to come to terms with the use of a smaller sample size which can be seen as a both a limitation and benefit of this method (Charlick et al., 2016; Smith et al., 2009). The limitation is that it was time consuming when looking for a population sample within a small group (Charlick et al., 2016). Involvement of a contact person (see Appendix B) was important so too make it possible to gather participants of this research. However, the benefit of using a small sample of participants is that I was also able capture in-depth accounts of participants' specific experiences (Charlick et al., 2016; Smith, 2004; Smith et al., 2009). In this respect, I found a "group for whom the research problem has relevance and personal significance" (Pietkiewicz & Smith, 2014, p. 4). The three theoretical underpinnings of IPA—phenomenology, hermeneutics and idiography— enabled me to gather "insights into the lives of people whose voices might not otherwise have been heard or whose experiences have been ignored" (Charlick et al., 2016, p. 213). Finally, the in-depth accounts of the participants that is provided by IPA researchers has the potential to "influence policy and practice" (Charlick et al., 2016, p. 213) and, I include the following policy and practice recommendations below.

6.4 Recommendations

The findings of this study have indicated the need to align policy and practices to work towards improving the situation for women with disabilities in rural communities in PNG. Great effort must be put into addressing some of the issues they encounter.

Firstly, policies and programmes that support and empower women, and people with disabilities should include programmes that raise awareness for people with disabilities (including women), so that they can be included and represented in their communities in terms of social participation and empowerment activities.

Secondly, policies and programmes designed for people with disabilities should effectively include women with disabilities so that women with disabilities in rural and remote areas are encouraged and supported to share their views and experiences of what their daily lives are like. The concerns about their situations can be heard when they are given opportunity to share their views and experiences. In this way, women with disabilities can be empowered to raise their concerns, and they can be acknowledged and recognised for their contributions in their communities. They can be valued, they can value their identity as disabled women, and they can be welcomed as fully competent members of the society. When policy makers and implementers are fully aware of their concerns, some improvements can be made.

Thirdly, the narratives in this thesis echo the voices of a minority group who are marginalised in their communities and do not have a voice. This thesis has given the opportunity to members of this group to address their concerns. I believe that when their concerns are heard and are made available to a wide range of audiences, possible positive measures can be taken to bring the voices of these women to platforms that can help address more of their concerns and develop means to help women with disabilities in PNG rural communities.

Finally, the findings of this study also reflect the poor mechanism and systems around the protection of the rights of women with disabilities in PNG. The findings indicate the need to work towards developing effective measures that promote the rights of disabled women in PNG. The study has also identified the need to bridge the gap between the daily experiences of disabled women and the policies and practices that relate to them as, *women with disabilities*. The findings of this research confirm the need to ensure that strategies and interventions to combat social exclusion, recognise women with disabilities as an explicit target group.

6.5 Implications for future research

This study articulated views and experiences of five participants from a rural setting in Papua New Guinea. Through their views and sharing of experiences, the complex nature of their lived experiences has been revealed. Since, little research has been conducted in the field of disability in PNG, this section offers some suggestions for potential research topics in this area.

1. Further study can be carried out on women with disabilities and what they know about the policies that relate to them.
2. Further study can be carried out on the views and experiences of children with disabilities in-/-out of schools.
3. Research could examine programmes that relate to women and girls with disabilities.
4. Further study could explore the views and experiences of men with disabilities.
5. A study could be carried out in the resource centres to present the gains and challenges of the programmes facilitated at the centres that include people with disabilities.
6. Research could indicate whether awareness programmes do change people's attitudes.
7. A study could be carried out to explore how able-bodied people perceive disability and disabled people.
8. A study could be carried out in the Community Development and Religion sector to explore how policy makers monitor and evaluate policy and practices that relate to women with disabilities.

6.6 Study Reflection

I recognised that enabling disabled women to 'speak out' would provide authenticity to the writings (Hans & Patri, 2003). I also recognise "that experience alone is not enlightening [.] [T]hough it is significant to our understanding; it requires both an interpretation and a conceptualisation as well" (Hans & Patri, 2003, p. 13). It is with this in mind that the disabled women's accounts of their daily life experiences have been developed into narratives and are presented in this thesis (see Chapter Four), so that the women's voices about their concerns about the realities they face speak for themselves.

This study has indicated the need to work towards promoting inclusion in communities so that women with disabilities are recognised, celebrated and embraced for their contributions in their communities, as disabled women. This can help develop self-esteem for these women. Equality of opportunity and fair and equal treatment for women with disabilities has yet to be achieved in PNG. In cases where women have the opportunity to partake in various activities, they should be empowered and supported to continue so that they realise their dreams.

6.6.1 My Hope

My greatest hope is that women living with disabilities in my society are given a voice through the voices of my research participants. This will also provide women with disabilities with awareness, identity and self-belief and confidence as women in their own right, with their own thoughts, their own values, opinions and ideas. To this end, their contributions in their communities can be valued, they can be empowered, and they can be respected for who they are. I also hope that sharing my experiences of using IPA as a research tool to explore the lived experiences of disabled women in a rural context as well as any other context can help future researchers who seek to explore lived experiences of disabled people. Finally, I envisage that the voice of women with disabilities in this thesis can influence the current policies and practices on 'women with disabilities' and aid policy makers to evaluate and review existing documents relating to women with disabilities in PNG. Moreover, it may identify and analyse factors that contribute to policies relating to women's rights, human rights and rights of disabled people. Effective policies can empower people with disabilities to live full and active lives as all people deserve. They can bridge policy and daily experiences. Thus, this study will endeavour to fill a gap in PNG and Pacific research surrounding women with disabilities.

6.7 Conclusion

In this study, four key experiential concepts of the views and experiences of daily life for women with disabilities were presented and discussed. These are: perceptions of self-related to the disability, positive perceptions: affirmations; marginalisation; and violence. This thesis found that disabled women are at an increased risk of what abled women are experiencing and, in continuing to live in silence, their concerns go unheard and their needs unmet.

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APPENDICES

APPENDIX A

Ethics approval

Te Kura Toi Tangata
Faculty of Education
The University of Waikato
Private Bag 3105
Hamilton, New Zealand, 3240

FEDU Ethics Committee

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07 8384500 ext. 7870
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THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

5 March 2019

Dear Alice

FEDU Ethics Application Approved-FEDU027/18

I am pleased to advise you that your ethics application for the project entitled "What are the views and experiences of daily life for women living with visible, physical disabilities in Papua New Guinea (PNG)?" was approved by Te Kura Toi Tangata Faculty of Education Ethics Committee on 13 April 2018.

Please be aware that the Te Kura Toi Tangata FEDU Ethics Committee must be advised (by memo) of any changes to the details recorded in your ethics application. Please send any such advice to fedu.ethics@waikato.ac.nz. You will receive a memo of approval once the change(s) has been considered.

We wish you all the best with your research.

Kind regards

Co-chairs
Te Kura Toi Tangata Faculty of Education Ethics Committee

APPENDIX B

Initial Invitation Letter to the Contact Person

9 Helena Rd
Hillcrest
Hamilton, 3216
New Zealand
Email: ayenas@hotmail.com
(+64) 0226878564
(+675) 79344230

14 March 2018,

Dear _____,

REF: **REQUESTING APPROVAL TO BE THE CONTACT PERSON FOR MY RESEARCH**

I am a University of Waikato Masters student on a research project on the views and experiences of daily life for women with visible, physical disabilities. My study aims to explore the views and experiences of women living with visible, physical disabilities in XXX, PNG. The research question participants will help answer:

> What are the views and experiences of daily life for women living with visible, physical disabilities in PNG?

I would like to request that you be the contact person between participants and I until I return to PNG. If you could identify and recruit prospective women whom meet the criteria for my research project (see criteria). As you are in contact with disabled women and have knowledge of their circumstances, and are trusted by them and myself could you help me identify and recruit four women with a visible, physical disability? In general, I want to interview women who were born with visible, physical disabilities and are able to communicate independently.

If you are willing to act as a liaison, I would request that you give your formal approval by signing the confidentiality agreement (see attached).
If you require further information regarding this research please feel free to contact my supervisor or myself.

Ashlie Brink /Lecturer
School of Human Development and Counselling
Faculty of Education /The University of Waikato
Private Bag 3105/Hamilton 3240 New Zealand
Phone: (+64) 7838 4466 ext. 7845.

I look forward to hearing from you.

Alice Yenas.

APPENDIX C

Contact Person's Confidentiality Agreement

In keeping with the requirements of the University's Human Research Ethics Regulations, I, _____, agree to be the contact person for this research that will be conducted by Alice Yenas as the final part of her Master's Thesis research work.

- My role is to act on her (Alice's) behalf to identify 4 prospective women with visible, physical disabilities and to speak to them on her behalf about becoming potential participants for the research according to her research criteria.

- While Alice is still in New Zealand, I will be the one to liaise with the women and I will be the one to communicate with Alice and her supervisor Ashlie, if there are any concerns from the participants or if there are any information to be passed on to the participants by Alice.

- In keeping with the requirements of the University's Human Research Ethics Regulations, I am required to keep all the information discussed between the participants, Alice and myself confidential as to maintain a high level of confidentiality as possible.

- During the process of liaising, identifying and recruiting potential participants for the research the participants' names will remain anonymous at all times.

Signed: …….. Date: ……..

APPENDIX D

Information for Contact Person

14 March 2018

I am a University of Waikato Masters student on a research project on the views and experiences of daily life for women with visible, physical disabilities. My study aims to explore the views and experiences of women living with visible, physical disabilities in XXX, PNG. The research question participants will help answer:

> What are the views and experiences of daily life for women living with visible, physical disabilities in PNG?

Please note:

- Participants are able to withdraw from the project at any time until the data analysis process has commenced.
- The information they give will be securely stored and used only for the purpose of the project.
- In keeping with the requirements of the University's Human Research Ethics Regulations the data collected must be archived indefinitely.
- General research results may form the basis of public and/or conference publications and presentations.
- Participants' names and comments will remain confidential throughout the research project, and in the resultant publications or presentations.
- An electronic copy of the completed thesis will become widely available as the University of Waikato requires that a digital copy of Masters Theses be lodged permanently in the University's Digital Repository: Research Commons.

Looking forward to hearing from you.

Alice Yenas

APPENDIX E

Recruitment Criteria for Contact Person

I wish to recruit and interview 4 women with visible, physical disabilities who meet the below criteria of my research project titled: What are the views and experiences of daily life for women living with visible, physical disabilities in Papua New Guinea?

Please see list below to help you identify women who may be suitable for my research. I am looking for:

- Women who are born with visible, physical disabilities
- Women who are able to verbally communicate without assistance of a carer
- Women who are young adults in the age category of 18 to 35 years
- Women who live within the greater XXX area

If they are interested in participating in my research and if they meet the above criteria, could you please gather their details for me to contact them on my arrival to PNG.

Thank you for your time.

Alice Yenas.

APPENDIX F

Information for Participants

14 March 2018

I am a University of Waikato Masters student on a research project on the views and experiences of daily life for women with visible, physical disabilities. My study aims to explore the views and experiences of women living with visible, physical disabilities in XXX, PNG. The research question participants will help answer:

> What are the views and experiences of daily life for women living with visible, physical disabilities in PNG?

Please note:

- Participants are able to withdraw from the project at any time until the data analysis process has commenced.
- The information you give will be securely stored and used only for the purpose of the project.
- In keeping with the requirements of the University's Human Research Ethics Regulations the data collected must be archived indefinitely.
- General research results may form the basis of public and/or conference publications and presentations.
- Your name and comments will remain confidential throughout the research project, and in the resultant publications or presentations.
- An electronic copy of the completed thesis will become widely available as the University of Waikato requires that a digital copy of Masters Theses be lodged permanently in the University's Digital Repository: Research Commons.

Looking forward to hearing from you.

Alice Yenas

APPENDIX G

Initial Invitation Letter to Participants

9 Helena Rd
Hillcrest
Hamilton, 3216
New Zealand

14 March 2018

Dear_____

Thank you for your interest in the research work I am undertaking as a Masters student in Disability and Inclusion studies at the University of Waikato. I hope that the information below will encourage you to participate in the project.

I worked with people with disabilities at the Special Education Resource Centre (SERC), in _____and later went to teach Special Education courses at the Teachers College.

The project will be the final requirement of my Masters degree and will be about the views and experiences of daily life for women with visible, physical disabilities.

I hope that you will agree to take part in my research, and we can then set up a convenient time and place for the interview. I envisage having a 1hour long recorded conversation with you about your views and experiences of daily life living with a visible, physical disability.

At our next meeting I will bring written consent forms for this project. Please be assured that all information is strictly confidential and that I am bound by the University of Waikato ethical codes of conduct concerning human research. Your name and comments will remain confidential throughout the research project and any future publications or presentations.

Looking forward to meeting with you.

With kind regards,

_____

Alice Yenas

APPENDIX H

Participants' Consent Form

Dear……..

Thank you for agreeing to participate in a project which is part of the Masters in Disability and Inclusion Studies degree. The question which guides my thesis is:

What are views and experiences of daily life for women living with visible, physical disabilities in Papua New Guinea?

I have approached you to take part in this study as a person who has information and insights that will be useful in my study.

Thank you for taking part on my study and I appreciate you taking time to share your knowledge and insights with me.

Please note that in this research:

- Your name will remain anonymous
- You are able to withdraw from the project at any time up until the data analysis process has commenced.
- The information you give will be securely stored and used only for the purposes of the project.
- In keeping with the requirements of the University's Human Research Ethics Regulations the data collected must be stored for an indefinite period of time.
- General research results may form the basis of public and/or conference publications and presentations.
- Your name and comments will remain confidential throughout the research project, and in the resultant publications or presentations.
- In any publications or presentations your anonymity will be preserved.
- An electronic copy of the completed thesis will become widely available as the University of Waikato requires that a digital copy of Masters Theses be lodged permanently in the University's Digital Repository: Research Commons.

In order to follow the University's procedures, I would appreciate your cooperation by signing the form below. If you are not able to sign, I will have your verbal consent recorded on the audio recorder as evidence or you can place an X in the space provided. If you have any questions, please do not hesitate to contact me or my supervisor (see below) for this research project:

Ashlie Brink (supervisor)
Email: ashlie.brink@waikato.ac.nz

Alice Yenas
Email: ayenas @hotmail.com

I understand the nature of this research which I am involved and understand that:

- My interview will be digitally recorded and transcribed verbatim by Alice and then translated into English used as part of her research.
- For confidentiality purposes all potential identifying information will be removed from Alice's analysis and that a pseudonym will be used to protect my identity. My name will remain anonymous.
- I can withdraw from the project at any time up until the data analysis process has commenced.
- My interview will be printed with pseudonyms and discussed with Alice's supervisor (Ashlie Brink).
- I will be given the chance if I wish to comment on the interview but I will not be able to change or add to them in anywhere.
- I can withdraw from Alice's study up until the data analysis process has commenced.
- I will be unable to withdraw my information from Alice's study after the data analysis process has commenced.
- The information I give will be securely stored in a password protected file in Alice's computer/memory stick and will only be used for the purpose of the project and my printed transcripts will be kept in a locked filing cabinet for up to five years after this study is completed.
- The requirements of the University's Human Research Ethics Regulations the data collected will be archived indefinitely.
- The general research results may form the basis of public and/or conferences publications of journal articles, presentations and teachings.
- I will own the interview contribution while Alice owns the write up of the research.
- In any publications or presentations my anonymity will be preserved.
- An electronic copy of the completed thesis will become widely available as the University of Waikato requires that a digital copy of Masters Theses be lodged permanently in the University's Digital Repository: Research Commons.

I would like to review my transcripts (please circle one) YES NO

I would like to have a summary of my transcripts YES NO

I would like to know the findings of the study YES NO

I will be contacted by PHONE

My phone number_____ Mailing Address

I agree to participate in this project.

Signed: _____ Print name: _____ Date: _____

APPENDIX I

Initial Open Ended Interview Questions

Question 1: How do you identify yourself?

How do you see yourself? What are some of the things that you do daily that makes you feel like you are a sister, daughter, mother, and woman?

Question 2: Tell me about what your day is like?

What kind of activities are you involved in? What kind of activities would you like to be involved in? Are there things that prevent you from being involved in some activities? What might they be? Are there other activities that you would prefer to do given a choice? Tell me about those choices.

Question 3: What sorts of difficulties do you sometimes face in your life?

How do you overcome them? What kind of extra support would have been helpful at that time?

Question 4: Tell me about your learning experiences?

What are some of the things you learnt in life? What would be some of the things you would want to learn? What would be some things you could have learnt to do but you were not able to? Why?

Question 5: Have there been times when your health or disability have impacted on your daily life? Can you share some of those times with me?

What were some of the difficulties you had at that time? What would have been most helpful for you? Why do you think that type of support was not available to you?

Question 6: Tell me about how you get from place to place?

What are some of your experiences moving around? Do you experience any barriers? What might these barriers have been? Would further support have helped you and in what ways?

Question 7: What are your relationships with others like?

In the community? Can you tell me about any social groups you belong to? What about contact or relationships with other women in your community? And other women with visible, physical disabilities? Do you ever come together as a group? Tell me more about that?

Question 8: To conclude, what would you say have been your greatest accomplishments?

APPENDIX J

Memo to Ethics Committee requesting retrospective approval for additional participant

To Oranga: School of
Human Development and
Movement Studies
The University of Waikato
Private Bag 3105
Hamilton, New Zealand

Phone 021415678
www.waikato.ac.nz

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

MEMO

To: Dr Nicola Daly
Re: Request to Include a Further Participant
Ethical Approval Number: FEDU027/18
Date: 06th August 2018

Dear Nicola

I conducted my research in PNG between May and June 2018. Upon arrival in PNG I met with my contact person (XXX) and she gave me the name of potential participant's according to my recruitment criteria (Appendix 4 on my Ethics Application). Rebecca's (pseudonym) name was on the name list of potential participants in the age category of 18- 35.

When I met with Rebecca and spoke to her about the interview she was happy and willing to be interviewed. She happened to be my third participant. She gave her consent by signing the consent form. At that time she told me she was 16 years of age. I then realised she was not in the age category of 18-35 but I could not stop the interview because she was happy and willing to share her story with me. I thought it would be upsetting to Rebecca if I had stopped the interview. So we proceeded with the interview. It went very well and Rebecca was happy to have worked with me.

The next day I called Ashlie Brink (who was my supervisor from February to June 2018) and mentioned to her that I had conducted an interview with a 16 year old girl. I explained how eager Rebecca had been to be interviewed and that I did not want to make her feel like her story was not good enough to be included. I said I was worried that the data I collected may not be used because she was not in the age category of my participants. Ashlie confirmed that I did the right thing by not stopping the interview because it would be upsetting to the girl if I had stopped. She advised me to interview 2 more who were between the age category of 18-35, which I did.

I sincerely request retrospective ethical approval to include this additional interview in my data set. Her story sits well within the rest of my data and I know she was happy to be included in my project.

Yours Sincerely

Yenas

Alice Yenas

APPENDIX K

Memo from Ethics Committee granting retrospective approval

Dean's Office
Faculty of Education
Te Kura Toi Tangata
The University of Waikato
Private Bag 3105
Hamilton, New Zealand

Phone +64 7 838 4500
www.waikato.ac.nz

THE UNIVERSITY OF WAIKATO
Te Whare Wānanga o Waikato

MEMORANDUM

To: **Alice Yenas**

cc: Dr Carol Hamilton

From: **Dr Nicola Daly**
Co-chair Faculty of Education Research Ethics Committee

Date: 7/8/18

Request for Extension to Research Ethics Approval – Student (FEDU027/18)

Thank you for your request for an extension to ethics approval for the project:

> **What are the views and experiences of daily life for women living with visible, physical disabilities in Papua New Guinea (PNG)?**

I am pleased to advise that the inclusion of data from the interview of one participant of 16 years old who gave their informed consent and followed the questions as approved in the original ethics application has received approval.

Please note that researchers are asked to consult with the Faculty's Research Ethics Committee in the first instance if any further changes to the approved research design are proposed.

The Committee wishes you all the best with your research.

Nicola Daly

Dr Nicola Daly
Co-chair Faculty of Education Research Ethics Committee